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# What We Know about Ethical Research Involving Children in Humanitarian Settings

An overview of principles,  
the literature and case studies

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Gabrielle Berman, Jason Hart, Dónal O'Mathúna, Erica Mattelone,  
Alina Potts, Claire O'Kane, Jeremy Shusterman and Thomas Tanner

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### **Correspondence should be addressed to:**

UNICEF Office of Research - Innocenti  
Piazza SS. Annunziata, 12  
50122 Florence, Italy  
Tel: (+39) 055 20 330  
Fax: (+39) 055 2033 220  
[florence@unicef.org](mailto:florence@unicef.org)  
[www.unicef-irc.org](http://www.unicef-irc.org)  
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# WHAT WE KNOW ABOUT ETHICAL RESEARCH INVOLVING CHILDREN IN HUMANITARIAN SETTINGS: AN OVERVIEW OF PRINCIPLES, THE LITERATURE AND CASE STUDIES

Berman, G.,<sup>a</sup> Hart, J.,<sup>b</sup> O'Mathúna, D.,<sup>c</sup> Mattellone, E.,<sup>d</sup> Potts, A.,<sup>e</sup> O'Kane, C.,<sup>f</sup> Shusterman, J.,<sup>g</sup> and Tanner, T.<sup>h</sup>

<sup>a</sup> Research Ethics and Facilitation Consultant, UNICEF Office of Research – Innocenti ([gabrielleberman@gmail.org](mailto:gabrielleberman@gmail.org))

<sup>b</sup> Department of Social and Policy Sciences, University of Bath ([j.hart2@bath.ac.uk](mailto:j.hart2@bath.ac.uk))

<sup>c</sup> School of Nursing and Human Sciences, Dublin City University ([donal.omathuna@dcu.ie](mailto:donal.omathuna@dcu.ie))

<sup>d</sup> Evaluation Specialist, Office of the UNICEF Representative of Cambodia ([e.mattellone@unicef.org](mailto:e.mattellone@unicef.org))

<sup>e</sup> Research and Evaluation Specialist, UNICEF Office of Research – Innocenti ([a.potts@unicef.org](mailto:a.potts@unicef.org))

<sup>f</sup> International Child Rights Consultant ([claireokane2008@gmail.com](mailto:claireokane2008@gmail.com))

<sup>g</sup> Planning Specialist Emergency Consultant, Office of the Regional Director, UNICEF CEE/CIS ([jshusterman@unicef.org](mailto:jshusterman@unicef.org))

<sup>h</sup> Climate and Environment Programme, Overseas Development Institute ([t.tanner@odi.org.uk](mailto:t.tanner@odi.org.uk))

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## Ethics at UNICEF

While this Working Paper specifically refers to research, the issues it raises are equally relevant to broader evidence generation activities including evaluations and data collection and analysis. This belief is consistent with the 2015 UNICEF Procedure for Ethical Standards in Research, Evaluation and Data Collection which acts as a reference point for this paper. Ethical principles are relevant and important within all evidence generation programmes that engage children, their families and their communities. A broader emphasis is in keeping with UNICEF's rights-based approach and its focus on equity and the rights of the world's most vulnerable children and their families. Any differences in outputs, methodologies and purpose between research, evaluation and data collection do not substantially alter the ethical implications and considerations in generating evidence. The duty of care and the requirement for ethical reflection should not be determined by the nature of the knowledge produced but rather by virtue of the nature and sensitivity of the data collection procedures and subsequent implications.

## Acronyms

AAP	Accountability to Affected Populations
CYP	Global Partnership for Children and Youth in Peacebuilding
DRC	Democratic Republic of Congo
FGD	Focus Group Discussions
IASC AAP	Inter Agency Standing Committee Working Group on Accountability to Affected Populations
LET	Local Evaluation Teams
OECD	Organisation for Economic Co-operation and Development
UNEG	United Nations Evaluation Group
UNFPA	United Nations Population Fund
UNCRC	United Nations Convention on the Rights of the Child (1989)
UNICEF	United Nations Children's Fund
WHO	World Health Organization

## Glossary of Key Terms

**Child** – Premised on the United Nations Convention on the Rights of the Child. For the purposes of this paper a child is defined as "a human being below the age of 18 years unless under the law applicable to the child, majority is attained earlier". However, this paper also explicitly recognises that while age may determine biological and neurological development, children's competencies are also shaped by their expectations, environmental, familial and cultural backgrounds and, importantly, by experience (Lansdown, 2005). Consequently, it is acknowledged that biological age may only provide a rough proxy for a child's capacities, particularly in extreme circumstances where adult roles may be, and frequently are, adopted by or imposed on children.

**Adolescent** – Adolescents are, in accordance with UNICEF, WHO and UNFPA definitions, defined as those persons aged 10-19 years; young adolescents are defined as persons aged 10-14 years; and older adolescents as persons aged 15-19 years.

**Evidence Generation** – In line with the UNICEF Procedure for Ethical Standards in Research, Evaluation, Data Collection and Analysis and for the purpose of this paper, research, evaluation, data collection and analysis are collectively referred to as evidence generation activities.

**Humanitarian (Emergency) Crises / Setting** – A humanitarian crisis or emergency refers to an event or a series of events in a country or region that causes serious disruption to the functioning of a society, resulting in human, material, or environmental losses which exceed the ability of the affected people to cope using their own resources. A crisis may be further classified according to its speed of onset (sudden or slow), its length (acute or protracted) or cause (natural or man-made hazard or armed conflict or a complex mixture) (IASC, 2015). For the purposes of this paper this will include prolonged emergencies in fragile states, where institutional arrangements embody and perhaps preserve the conditions of crisis (Putzel, 2012).

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# 1 WHAT WE KNOW ABOUT ETHICAL RESEARCH INVOLVING CHILDREN IN HUMANITARIAN SETTINGS: AN OVERVIEW OF PRINCIPLES, THE LITERATURE AND CASE STUDIES

## 1.1 Executive summary

This working paper identifies and explores the issues that should be considered when undertaking ethical research involving children in humanitarian settings. Research grounded in sound ethical principles is critical in ensuring that children's rights are respected throughout the process and beyond and that the research itself is relevant, useful and valid. This paper examines both the universal (i.e. relevant to all research involving children) and specific ethical issues that may arise when involving children in research in humanitarian settings. This is undertaken through an examination of the literature, a review of relevant case studies and a reflection on the ethical issues highlighted in UNICEF's *Procedure for Ethical Standards in Research, Evaluation, Data Collection and Analysis* (the *Ethics Procedure*).<sup>1</sup> The latter is used as a baseline for generic ethical standards when involving children in research.

The key findings of this overview highlight that many of the ethical issues that are present in other settings remain relevant and applicable in the context of humanitarian settings. These ethical issues include: an institution's capacity to appropriately and respectfully engage children in research, understanding power relations, securing informed consent and assent, ascertaining harms and benefits, maintaining privacy and confidentiality, and ensuring appropriate communication of findings.

Importantly though, humanitarian contexts present extreme circumstances where each of the issues noted are likely to present greater challenges and complexities. Further, the implications of not reflecting on and mitigating against these difficulties could have far greater consequences for both the short and longer term safety and well-being of children and their communities. In spite of this, the literature in this area is under-developed and the issues require further engagement and ongoing reflection.

The aim of this paper is firstly to highlight the need and value of engaging children in research in these settings. Second, it provides a broad overview of the key ethical considerations that those commissioning or undertaking research need to reflect on when proposing, designing or implementing research programmes in these complex settings. To this end the general ethical principles for research involving children are examined with explicit reflection on UNICEF's *Procedure for Ethical Standards* (UNICEF, 2015). Based on these principles and the findings from a literature review conducted for this paper, seven categories of ethical issues were identified and examined in detail. Several case studies are also included to provide examples of how ethical issues have been raised and addressed in research involving children in humanitarian contexts. Following analysis of the ethical issues, Appendix 1 provides a list of questions designed to trigger reflection about each of these. Appendix 2 then provides an annotated summary of excerpts from key documents from the literature review that specifically explore ethical issues arising in research in humanitarian contexts. Appendix 3 includes excerpts from the UNICEF *Procedure for Ethical Standards in Research, Evaluation, Data Collection and Analysis* (UNICEF, 2015a) as a reference point for work undertaken in these domains.

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<sup>1</sup> See Appendix 3 for details.



It is clear that further work remains to be done on this important topic. We do not claim to have identified every ethical issue regarding children's participation in research in humanitarian settings. Nor do we claim that our suggested responses for addressing ethical issues are the only possibilities or always the best ones for any specific context. The intention is to provide a comprehensive overview of this topic in order to raise awareness of its relevance and importance, and to encourage further discussion, debate, reflection and scholarship in this area. We will continue to work on this topic and the specific issues, and welcome input that will constructively critique this paper and help to improve its future versions.

## **1.2 Methodology and audience**

Current and available literature exploring ethical issues when involving children in research in humanitarian contexts was reviewed. A number of approaches were adopted to capture as much available evidence as possible across a number of sources. In the first instance, journal articles were sourced through open access journals, and online research network platforms such as Research Gate, National Academies Press and Academia.edu using the terms 'ethics', 'ethical', 'research', 'children', 'humanitarian', 'emergency', 'natural disasters', and 'conflict'. In addition, a database of over 300 articles on ethical research issues involving children from [childethics.org](http://childethics.org) was similarly searched. The same search terms were used to source relevant grey literature and working papers through the internet via both Google and Google Scholar. It should be noted that this was a 'preliminary search' rather than a systematic review, which may be undertaken in the future.

The relevant documents identified were analysed to determine the nature of the ethical issues raised for research involving children in humanitarian settings. Some of the documents were particularly relevant to this working paper because they included lists of ethical principles, ethical frameworks for researchers, or checklists for ethical reflection in research. Those that were most relevant are discussed in Appendix 2. In some cases, an annotated summary is made of the source, and in other cases excerpts are provided (with permission). Appendix 3 provides extended excerpts from the UNICEF Procedure for Ethical Standards in Research, Evaluation, Data Collection and Analysis (2015).

While this literature review is not exhaustive, the findings indicate that the literature pertaining to ethical issues and frameworks for involving children in research in humanitarian contexts is an emergent but still relatively under-developed area. Several documents emphasize this finding (Gibbs et al., 2013; Cahill et. al, 2010). In an attempt to address this limitation and, where clear gaps appear in relation to guidance on the ethical issues of involving children in research in these settings, reference is made to relevant:

- i literature, frameworks and guidance relating to ethical research involving children, and,
- ii literature, frameworks and guidance on ethical issues arising from broader human subject research in humanitarian contexts.

The case studies chosen were provided by the authors to reflect the issues emerging from the literature.

On a final note, the target audience is not only those wishing to carry out research involving children in these environments but also humanitarian actors commissioning or contracting out research. It is hoped that this review may raise awareness of relevant issues that programme managers and other frontline workers need to take into account to ensure effective oversight of research undertaken on their behalf.

### **1.3 A brief note on age**

In referring to children we adopt the definition of the child as expressed in Article 1 of the United Nations Conventions on the Rights of the Child (see Glossary). The terms ‘youth’ or ‘young person’ are not defined in international law, but are variously applied to 15- to 24-year-olds by UN Agencies. Adolescents are referred to only when expressly defined in the literature, though the ethical issues referenced in this paper could just as easily apply to older adolescents (see Glossary).

It should be emphasised that biological age may only provide a rough proxy for a child’s capacities, particularly in extreme circumstances where adult roles may and frequently are, adopted or imposed on children. Further complicating this matter is the fact that birth registration papers may be lost or may not exist and consequently children’s ages may not be known. As such, ethical research must explicitly take into account children’s competencies and their lived experiences as well as cultural understandings of childhood and children, not merely their biological age.

## 2 WHY ENGAGE CHILDREN IN RESEARCH IN HUMANITARIAN SETTINGS?

### 2.1 The gaps and need for research involving children

*Further research is needed to ensure that we can fully understand children's perspectives on their roles and what is supportive for positive disaster recovery.*  
(Gibbs et al., 2013)

Proponents of research, evaluation and data collection programmes involving children in humanitarian contexts note the paucity of knowledge and evidence in this field (Gibbs et al., 2013; Cahill et al., 2010). They argue that appropriate and ethical research is necessary to fully appreciate children's lives, understandings, attitudes, behaviours, environment and health within the difficult and frequently unstable conditions that arise during and after humanitarian crises (Clarke et al., 2014). These researchers note the critical importance of children's participation in decision making on issues that affect them, and consequently, the need for their input into evidence-generating activities that inform decision making in these contexts. Children can also provide valuable insights into issues that may be seen primarily as adult issues, and thus their participation should be considered in all research, just as adults may have valuable insights into children's issues. Other commentators have noted that the dearth of research in this area may limit our understandings not only of the risks children are exposed to, but also of effective coping strategies and factors that support their resilience, their broader and longer term development, and their well-being. These include the programmes, physical environments, networks and roles that may allow children to flourish in these difficult contexts.

*Our understanding of the complex ways in which conflict impacts upon children is still partial and sketchy. While the emergence of diverse risks in conflict settings has been noted, the actual processes by which these are manifested in children's everyday lives are generally not well understood; nor do we have an in-depth or sufficient understanding of how children respond.*  
(Hart and Tyrer, 2006)

Children often face challenges to their physical, emotional and intellectual development due to their age, gender, ethnicity/religion, socio-economic position or other factors that limit their power or status within a community. In humanitarian settings, such challenges are often compounded by the breakdown of systems and structures necessary for children's support and development (National Research Council, 2002). For this reason, special measures are required to ensure children's needs are met, for their protection, survival, well-being and to preserve their opportunity to grow, develop and reach their full potential. In research designed to address these challenges, children's voices are of critical importance (The Sphere Project, 2011; National Research Council, 2002).

Within the broader discourse on the need for research involving children in humanitarian contexts, it is critically important to recognise that children are not a homogenous group. As noted by Feinstein and O'Kane (2008a):

*There is increasing recognition that children's experiences of childhood are diverse and are affected by gender, age, dis/ability, level of family income, ethnicity, culture, religion, geography, socio-political context and other factors.*

Consequent to this diversity, recognition is required that particular groups are frequently marginalized, under-researched and under-engaged, and face specific challenges and vulnerabilities. However, beyond merely addressing their particular vulnerabilities, as noted above, an understanding of their contexts, resources, understandings and life skills can provide a rich source of information. Research programmes targeting specific cohorts offer the potential to give voice to marginalised or under-researched groups and to their experiences, to better target interventions and where possible, to empower and build on pre-existing capacities and skills that can be easily ignored within a broader child protection paradigm (Cahill et. al., 2010). This in turn can positively impact our ability to address and intervene in ways that reflect the 'best interest' of the child, with the appreciation that an adult's perceptions of 'best interest' can, at best, go only part way to understanding and addressing the complexity of the ecological systems of children in humanitarian contexts.

## **2.2 The value and contribution of children and young people to research in humanitarian settings**

As noted by Zwi and Grove (2006) children's perspectives and participation are important, and research involving children can offer valuable new insights which have the potential to lead to more effective interventions for both children and adults.

With respect to social and behavioural research, Laws and Mann (2004) argue that children's participation often produces better quality data about issues that affect them than research that exclusively consults adults. They reason that active engagement by children helps focus research and clarifies the analysis and interpretation of data. Further,

- Obtaining data from children themselves increases the possibility of presenting a picture that better reflects their experiences and situations and reduces misinterpretation by adults.
- Adult researchers may have less insight into the daily lives of children than they think they have, particularly during and following humanitarian crises. In much of the world, children's lives have changed dramatically over the last generation. New risks have emerged or expanded (e.g. conflict, natural disasters, climate change, or HIV/AIDS) but tremendous advances have also been made (e.g. in child survival, in reducing hunger, or in expanding access to education). Other transformations could be argued to have brought both positive and negative changes in the vast array of factors shaping children's lives (e.g. the emergence and pervasiveness of the Internet and the rise of globalization).
- Children constitute a significant proportion of the global population and in some communities they are the majority. Consequently, the natural way to obtain information is to work with children as participants, informants and/or researchers. (Laws and Mann, 2004)

Emerging research also suggests that children have a unique perception of disaster and conflict risks, combining external information with their own experiences, and are able to communicate these perceptions to others to bring about changes in behaviour that can reduce risks and vulnerabilities (Tanner, 2010). Research is needed to understand how children have experienced a past humanitarian crisis and how they continue to experience life in its aftermath; such analysis requires direct engagement with children. Research on children's perspectives and approaches can provide practical insight on how they can alter their own risk behaviour on the household and community scale, while also mobilising adults and external policy actors to change wider determinants of risk and vulnerability (Tanner et al., 2009; Mitchell et al., 2009).

### **2.3 The value to children**

Understanding the impacts (both positive and negative) of involving children in research in humanitarian settings is a relatively nascent field of interest. However, current evidence suggests that appropriate and targeted participatory research and evaluation involving children in humanitarian settings can have a number of positive impacts, including:

- At an intellectual level: improving their capacity to determine how to access information and analyze findings, enhancing their decision-making capacities, and supporting the development of their abilities to discern and determine what information is important.
- At a personal and psychological level: providing a greater sense of engagement and purpose, supporting a greater sense of personal identity; understanding of the experience of the crisis and its impacts; and providing a heightened sense of self-respect and self-esteem.
- At a social level: fostering and developing negotiation skills, interpersonal skills, relationships and networks as well as providing an increased sense of responsibility for themselves as well as for others (Hart and Tyrer, 2006; Gibbs et al., 2013, Feinstein, and O'Kane, 2008b).

While an understanding of the value of research involving children in humanitarian settings is important, the methods and approaches used must be ethical, appropriate and rigorous. They must also protect, respect and reflect the capacities of the children involved. In this way, meaningful and positive involvement of children in research can benefit both the actors involved in humanitarian settings and, importantly, the children themselves.

**Case Study: The Benefits of Research Involving Children in Humanitarian Contexts:  
The child fosterage and child domestic work in Haiti programme (Cayemittes et al., 2014)**

A study was undertaken in Haiti to determine child fosterage and child domestic work prevalence and practices, and to explore how children's living conditions and situations developed in these arrangements from 2001 until 2014. The study involved a nationwide household survey (including a questionnaire specifically designed for a randomly selected child in each household) and qualitative fieldwork involving children. In the aftermath of the 2010 earthquake, questions were asked about changes to: how children were recruited to domestic work, the motivations of children, parents and caretakers regarding children's relocation, and the role of incentives connected with aid and disaster relief efforts in the cities. Importantly, the study also allowed for reflection on Haitian children's motivations and life experiences in domestic work. In addition, the research allowed exploration of issues and impacts of the last drought in 2013/2014, and individual life histories in the aftermath of the 2010 earthquake from current and former child domestic workers, and other children living away from their family of origin (in different forms of living arrangements).

Findings showed that education is one of the most important factors to these child workers with respect to their aims in life, and feelings of inclusion and exclusion in both society and family life. Findings also indicated that they view education as an important aspect of personal fortune and sense of self-worth, and expend much effort to cover educational expenses. Younger children were also found to be remarkably concerned with education.

The desire to learn is reflected by Maria, a girl of 15 who has lived with an aunt since the earthquake in 2010. Maria is currently not in school. In her aunt's house, she does the washing up, dusts, and washes clothes for her aunt. Maria says her aunt treats her badly: "She hits me and I can't hit her back. She is more affectionate towards her own children." Maria hopes a local NGO will help her go to school, but if this is not possible, she says she will try to get an income. Maria speaks as if her aunt's home is not "her home", but that she can relate to her aunt's wish to move out of Port-au-Prince, and adds that, "wherever I can go to school, that's my home" (Cayemittes et al., 2014, pp. 58-59).

During similar fieldwork in 2001, many children as well as adults portrayed informal learning of life skills as important (Sommerfelt, ed, 2002, pp.60). During fieldwork in 2014, however, the emphasis had shifted: though informal training was still described as a resource, children viewed formal education as a prerequisite for success (albeit an insufficient one). This emphasis was more striking than in 2001. Conversely, children in the 2014 study viewed not going to school as denigrating, particularly when it reflected differential treatment from other children in a new household. These types of findings highlight not only the critical importance of children's voices, but also that children's attitudes and perceptions are not static and that ongoing research involving children is critically important to understanding their changing attitudes and perceptions in an evolving landscape.

### 3 WHY EXAMINE THE ETHICS OF UNDERTAKING RESEARCH INVOLVING CHILDREN IN HUMANITARIAN SETTINGS?

The complexity of humanitarian settings creates significant challenges to the integrity of research conducted in this context and raises a number of ethical issues. As noted by O'Mathuna (2010), the ethical implications may differ by magnitude as they,

*... involve a number of distinctive factors, including the degree of devastation affecting participants and the urgency often involved in initiating research projects. Such factors generate ethical issues not usually encountered with other types of research, and create tensions that must be taken into account in designing and conducting disaster research so that it attains the highest ethical standards (p.65).*

The particular challenges to undertaking research involving children in emergency and fragile contexts, as opposed to more stable settings, include:

- The impact on children of participating in the research process, associated with more acute and heightened physical, emotional and social vulnerability arising from security issues, volatility and instability;
- Equity issues relating to inclusion and exclusion and the provision of compensation, payment or ancillary services in contexts of extreme resource scarcity;
- The speed and scale at which programming and consequently research needs to be undertaken in order to meet urgent and immediate needs and the consequent ethical and methodological challenges;
- Obtaining and ensuring ongoing consent in the face of high proportions of unaccompanied or separated children, and the challenge of ascertaining competencies and agency of children given changing roles and exposure to extreme circumstances.

Despite the complexities arising from these settings, there is only a nascent body of literature exploring the engagement or involvement of children within such contexts. Research is critical to understand the interactions between individual factors (i.e. age, gender, dis/ability) and environmental factors (i.e. social, economic, cultural, political), and how these may heighten vulnerabilities or support resilience (CP MERG, 2012). Guidance to increase understanding of the particular ethical issues arising from children's involvement in research in volatile contexts is therefore required. Without this understanding, a number of negative outcomes may result, including:

- Significant exposure to risk with the potential for harm to: child participants, their families and/or communities as well as to researchers or enumerators, and to the reputation of the organization;

- Poorly designed research that produces unreliable or inaccurate data;
- Missed opportunities to obtain children's perspectives on a wide range of issues, not just those considered 'children's issues';
- Silencing or misrepresentation of children with insufficient attention to their diversity and experiences, resulting in policies and programmatic responses that fail to meet their needs and long term development;
- Infringement of individual children's rights as well as negative impacts on children as a social group.



## 4 CRITICAL ISSUES IN UNDERTAKING RESEARCH INVOLVING CHILDREN IN HUMANITARIAN SETTINGS

The following sections provide a broad overview of issues to be considered when planning and conducting research with children in such sensitive situations, drawn from the literature and guidance documents available (see the section on 'Methodology and audience' for further details). As there is a dearth of literature focusing on this aspect of ethics and research (Gibbs, 2013; Cahill et al., 2010) relevant issues and references from both the broader literature and contexts that are not specifically humanitarian have been noted. Appendix 2 provides annotated summaries and excerpts from the key documents identified in the literature review for this working paper. With this in mind, the following section reflects on the broader principles that guide ethical research at UNICEF and that remain relevant when undertaking research involving children in humanitarian settings.

### 4.1 Principles of ethical research involving children

The *UNICEF Ethics Procedure* establishes the ethical standards for all research, evaluation, data collection and analysis undertaken across the organization. (See Appendix 3 for further details). The *Ethics Procedure* reflects both international ethical standards (CIOMS, 2002; The Belmont Report, 1979) and organizational knowledge. Unlike traditional standards however, it has a particular focus on research involving children (Graham et al., 2013), and adopts a child rights based approach.

The following are the key principles for ethical evidence generation (including research) at UNICEF.

#### *i - Respect*

All evidence-generating activities should ensure respect for all persons. Respect demands that individuals be treated as capable of deliberation about personal goals and of acting under the direction of such deliberation. To respect a participant in research is to give weight to their values, preferences, and beliefs and to recognise their capability for self-legislation, their ability to make judgments, to state their opinions and to make choices.

Respect also implies an understanding that an individual also has a relational self and that adults or children are bound up in complex relationships of inter-dependency. Hence respect requires an understanding that decision-making is made in a broader social context and that personal agency may be limited due to age, circumstance or personal capacities. In this context, respect requires recognition of capabilities, power differentials and the degree of agency that an individual may have. In the context of research involving children, respectful evidence generation needs to be situated in their lived experience, recognizing the reality of unequal relationships of power that frequently exist. It must create environments that support their personal agency and their dignity. In relation to children, respect implies recognition of their evolving capacities (Lansdown, 2005).

#### *ii - Beneficence and Non-maleficence*

*Beneficence* – The principle of beneficence refers to the requirement that actions within evidence-generating activities promote the well-being of individuals, communities or society as a whole. The principle of beneficence requires the identification of clear benefits likely to arise

from evidence generation activities and to reconsider proceeding if these cannot be articulated. Beneficence includes the concept of reciprocity, whereby the evidence generated is conveyed back to the participants so that they may triangulate findings, contextualize their participation and potentially gain from the knowledge disseminated.

*Non-maleficence* – The principle of non-maleficence, doing no harm, requires avoiding or minimizing harm or injury to participants, through acts of either commission or omission. While the primary purpose of research, evaluation, and data collection and analysis is to generate new evidence, this goal should never take precedence over the rights of individual participants. Non-maleficence requires an examination of the profile, competencies and skills of researchers and enumerators to ensure no harm comes to participants by virtue of inappropriate, unskilled or incompetent researchers or enumerators. It also requires explicit consideration of means to ensure the privacy of participants, their safety and any possible negative impacts arising from participation.

### ***iii - Justice***

The principle of justice requires that consideration is given to who benefits and who bears the burdens of the evidence generation. One application of justice is that due reflection is given to determining the appropriateness of proposed methods of selecting participants.

Other considerations include: the allocation of scarce resources to research as opposed to direct aid, effective dissemination of results, and whether and how any payments or ancillary benefits are distributed to participants.

With respect to issues highlighted in the Ethics Procedure, standards (excluding those related to organizational process) are clustered into five main areas namely: harms and benefits, informed consent, privacy and confidentiality, payment and compensation, and conflict of interest (refer to Appendix 3 for further details). The following section explores these issues and notes where further detail and reflection is required to address the specificities of research undertaken in humanitarian environments.

## **4.2 Ethical issues: literature and case studies**

Within the broader framework outlined above, and drawing from current literature and case studies, the specific ethical issues and challenges of undertaking research involving children in humanitarian settings can be broadly grouped into seven categories. These reflect the particular specificities of the context and the more nuanced considerations across the research cycle.

These categories are:

- Institutional capacity to ethically involve children in research
- Understanding power relations
- Harms and benefits
- Informed consent and capacities of participants
- Privacy and confidentiality (including ICT)
- Payment, compensation, ancillary services and reciprocity
- Communication of results

The following sections demonstrate that while broader ethical issues pertaining to research involving children in these contexts can be raised, it is ultimately careful examination of, reflection on, and discussion of a particular humanitarian setting that is critical. This requires that the geographical, political and social landscapes and the populations involved be explicitly considered in the coordination of relevant parties and agencies and the development of protocols and actions to be taken to address or mitigate against possible and unforeseen ethical issues.

Appendix 1 (page 43) provides a checklist and possible responses for each of the issues identified in Table 1. The following sections discuss these in more detail.

**Table 1 – Ethical issues to consider when involving children in research in humanitarian contexts**

INSTITUTIONAL CAPACITY	POWER RELATIONS	HARMS AND BENEFITS	INFORMED CONSENT	PRIVACY AND CONFIDENTIALITY	PAYMENT, COMPENSATION AND ANCILLARY SERVICES	COMMUNICATION OF RESULTS
Consistency with broader humanitarian principles	Relationships between investigators, interpreters and communities/care givers	Evaluating risks and benefits	Challenges of informed consent with unaccompanied minors	Culture, age and context appropriate approaches to privacy	Meeting need versus payment and compensation	Reviewing reports prior to dissemination
Vetting and training of staff to work respectfully with children and their communities	Relationships between different children	When NOT to include children in research in these contexts	Determining competency to consent	Data confidentiality and security (including use of ICT's)	Consulting humanitarian actors on the need or approach to compensation	Triangulation and feedback into communities
Clear child protection protocols (including access to psycho-social support services)	Relationships between adults and children within communities and settings	Engaging children to understand, inform and reflect on risks	Ensuring ongoing consent		Opportunity cost of children's participation	Using research for change
Considering the implications of mandatory reporting	Researchers' relationship with children	Environmental safety and security (of children and staff)			Equity, voluntariness and avoiding coercion	
Avoiding tokenism: institutional will to listen to children's priorities or to acknowledge limitations to doing so	Researchers' relationship with communities	Appropriate methods and implementation			Reciprocity	
		Taking photographs or videos				

### 4.3 Institutional capacity to ethically involve children in research

#### Key issues to consider

- Consistency with broader humanitarian principles (leadership/governance, transparency, feedback and complaints, participation, and design, monitoring and evaluation)
- Vetting and training of staff to work respectfully with children and their communities
- Clear child protection protocols
- Considering the implications of mandatory reporting
- Avoiding tokenism: institutional will to listen to children's priorities or to acknowledge limitations to doing so

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**Consistency with broader humanitarian principles:** The institutional capacity to ethically involve children in research is a key issue identified in the literature. This consideration is also in keeping with broader humanitarian guidance. One of the seminal pieces of guidance in this area is the Commitments to Accountability to Affected Populations (IASC AAP; 2011) (Commitments to AAP). The five commitments espoused are leadership/governance, transparency, feedback and complaints, participation and design, monitoring and evaluation. While the Commitments to AAP pertain primarily to humanitarian action, they are relevant to research efforts in this domain. The Commitments to AAP can provide some guidance relating to the obligations of research teams and their institutions (including institutional review boards and research ethics committees) to ensure that research is consistent with the principles under which humanitarian actors operate. These commitments have several practical implications that can be applied to research practice including the need for:

- Appropriate engagement with communities, highlighting a moral imperative to undertake non-extractive<sup>2</sup> research and/or to ensure a degree of reciprocity (leadership and governance, participation);
- Appropriate recruitment, training and oversight of researchers in the field, particularly as pertains to researchers working with children (leadership and governance). This includes developing researcher reflexivity where the researcher pays particular attention to the impact of the research on children (Connolly, 2008);
- Clear disclosure to and consultation with the communities and children involved in projects about the nature of the research and the methods adopted (transparency);
- Appropriate representation and non-discrimination in the selection of participants (participation);

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<sup>2</sup> Non-extractive research refers to research that does not merely seek to take from communities (in terms of their time, efforts and information) but rather also seeks to give back in some measure.

- Ensuring coordination with pre-existing formal complaints mechanisms (coordinated inter-agency complaints mechanisms), and providing clear information to participants and their community about accessing these processes (feedback and complaints);
- Ensuring appropriate feedback is provided to participants and their communities, preferably streamlined into existing and appropriate programme feedback mechanisms and channels (feedback and complaints).

**Vetting and training staff to work respectfully with children and their communities:** Extrapolating from these commitments, institutions instigating or supporting research have an ethical responsibility to appropriately resource, vet, train and support staff involved in such projects.<sup>3</sup> Staff must be fully aware of the need to appropriately engage, consult and work, wherever possible, in collaboration with the coordinated institutional frameworks which operate in the field. Further, they need to understand the implications of ethical principles for their work and reflexively consider these principles, including non-discrimination and representation and how to work sensitively and respectfully with children in these difficult contexts (Laws and Mann, 2004; WHO, 2007; IASC AAP 2011).

*Service providers need to employ various techniques to help facilitate communication according to age and developmental levels. Service providers should be skilled in verbal and non-verbal communication techniques, as some children may not be able to find the words to share important information – because of age or because the challenge of recalling the trauma is overwhelming.* (IRC, 2012a)

When involving human subjects in research, and particularly children, the competencies, attitudes and skills of the researchers will define both the experience and responses of children involved. The humanitarian context heightens the need for those interacting with children to have the right skills and sensitivities in light of the extreme circumstances and experiences that many children are likely to have faced (Feinstein and O’Kane, 2008b).

**Clear child protection protocols:** In ensuring children are protected during research, clear child protection protocols are required. Protocols may address issues such as what to do if a child becomes visibly distressed; how to detect indirect signs of distress; how to decide when immediate support is required (including health services) (IRC, 2012a; Hart and Tyrer, 2006), or what to do if risk of serious harm is disclosed (Laws and Mann, 2004). Further, as noted by the IASC AAP (2011), appropriate child friendly feedback and complaints mechanisms need to be reflected in any protection protocol to ensure that children and communities are able to feel comfortable and safely report unethical behaviour of staff.

<sup>3</sup> For resources on training staff to work sensitively with children see:

*Communicating with Child Survivors Attitude and Communication Tools found in the Caring for Child Survivors of Sexual Abuse: Guidelines for health and psychosocial service providers in humanitarian settings by the International Rescue Committee.* Available at: <http://gbvresponders.org/response/caring-child-survivors>

The literature also clearly notes the need for psycho-social services to be available for immediate support and for referral protocols for children at risk or for those who may become distressed consequent to the research process (Hart and Tyrer, 2006; Feinstein and O’Kane, 2008b; Laws and Mann, 2004). As noted by Devries et al. (2015), when resources are scarce,

*...finding local services that can provide appropriate support for children may be challenging, and researchers need to have concrete plans and back-up plans in place to ensure that obligations can be met. (p.1)*

If the capacity to provide support services for children cannot be met, then, as noted by Ford et al. (2009), potential harms will need to be weighed against potential benefits to determine whether or not the research should be undertaken (see section on harms and benefits below for further discussion). In the absence of support services, the likely impact of the research on children and their communities will need to be carefully considered through appropriate consultation with communities and other humanitarian actors.

**Considering the implications of mandatory reporting:** If, after careful consideration and consultation, a decision is made to undertake the research, protocols for reporting past, current or potential abuse of children to authorities must be considered, particularly in locations where mandatory reporting requirements exist. Given the potential breakdown or impotence of justice, legal, and social services, and police systems, understandings of relevant legislation, enforcement and available supports as well as appropriate and clear processes for any mandatory reporting of abuse are critical (Feinstein and O’Kane, 2008b; Devries et al., 2015). In all instances, the best interests of the child need to be prioritized. As noted by the International Rescue Committee (2012):

*Mandatory reporting requirements can raise ethical and safety concerns in humanitarian settings, where governance structures often break down and rule of law either does not exist or exists only in theory but not in practice. In emergency settings, where established and safe mechanisms to report child sexual abuse might not exist and where security can be unstable, mandatory reporting can set off a chain of events that potentially expose the child to further risk of harm, and as such it may not be in the child’s best interest to initiate a mandatory report... service providers are advised to use the central guiding principle – the best interests of the child – to guide decision-making in child-centered service delivery.*

**Avoiding tokenism:** institutional will to listen to children’s priorities or to acknowledge limitations to doing so: Aside from issues relating to procedures and processes to support vulnerable children within the research programme, the literature also provides clear guidance regarding the need for institutional will to ensure that children’s voices are heard and responded to, even if their priorities are not in line with organizational and funding priorities (Tanner, 2010; Tanner et al., 2009). This is consistent with the Commitments to AAP (2011) and the need for appropriate governance and leadership of the implementing agency. This issue is explored in the case study below.



**Case Study: Responding to Children's Priorities: Understanding vulnerability relating to climate change with children in the Philippines** (Haynes and Tanner, 2015)

A programme to highlight and understand perceived risks, vulnerabilities and opportunities for risk reduction for children who are impacted by climate change was undertaken utilizing participatory video with children's groups in the Philippines. These videos and the programme itself revealed the socially constructed nature of climate change and disaster risk.

School education on climate change led the groups to identify the changing climate as a cause of rising hazard burden, for example through more intense rainfall leading to greater floods. However, children's investigation and action plans demonstrated how risks result from a combination of exposure (such as coastal and riverbank village location) and sensitivity (e.g. through climate-sensitive livelihood activities, poor infrastructure, high malnutrition levels, or lack of engagement in decision-making processes).

The initial action plans resulting from the programme focused largely on social vulnerabilities such as education, infrastructure and employment issues, while the focus on climate change was downplayed by a number of the groups. This created ethical difficulties for the researchers, who came with pre-existing research agendas and a funding mandate to highlight climate change and related disaster risk reduction activities. This led to the researchers and funders influencing the selection of the natural hazard-related elements of the children's vulnerability, capacity and risk assessments as the focus in the process of creating the participatory videos. While this still represented a major concern given the incidence of flooding in all communities, there were significant ethical issues relating to the de-prioritization of children's concerns. This had the potential to disempower the children's groups as their priority foci for the films and subsequent risk reduction actions and lobbying did not address some of their primary concerns.

The case study above identifies the ethical dilemma of attempting to engage children in a participatory manner. It highlights the importance of ensuring that the organization and research team are willing to listen to recommendations and priorities of children if they conflict with funding and organizational imperatives. Further, it clearly illustrates the importance of explicitly articulating to children what the parameters of the programme are, such that consultations (such as asking children to identify what their priorities are) are not viewed as tokenistic, nor raise expectations regarding the capacity of children to determine the nature/focus of the research agenda and programme.

In line with the Commitments to AAP, ethical research would ensure that, wherever possible and appropriate, participants, namely children, play an 'active role in the decision-making processes that affect them' (IASC AAP, 2011). In scenarios where it may not be possible to give children that role, this should be reflected upon from the outset, or as soon as this becomes evident, to ensure that children are clearly informed as to any limits to their participation and influence within the research. The nature and scope for participation should always be clearly defined and transparently conveyed during the consent process. This would include any potential limitations in researchers' or their institutions' ability to act on the findings and priorities of the children and communities involved. This should also include clear articulation of their capacity to advocate on behalf of children if requested.

## 4.4 Understanding power relations

### Key issues to consider:

- Relationships between investigators, interpreters and communities/caregivers
- Relationships between different children
- Relationships between adults and children within communities and settings
- Researchers' relationship with children
- Researchers' relationship with communities

Power dynamics are explicitly identified as an ethical consideration when involving children in all research contexts (Alderson, 1995; Alderson and Morrow, 2004; Graham et al., 2013). Ethical research guidelines highlight that social dynamics should be understood and factored into all stages of the research, requiring a clear understanding of the roles and the distribution of power within the particular location and context (Hart and Tyrer, 2006). Researchers should seek to understand and address the social context and complex power relations that may exist between various stakeholders, at every stage in the research process. Undertaking research with children in humanitarian contexts frequently makes this task more difficult in light of new or rapidly changing hierarchies and roles of children and the potential for heightened risk for particular cohorts of children (i.e. those from minority groups, children with disabilities, or from lower families of socio-economic status, particular genders etc.). The following are therefore the key dynamics and issues that have been identified in the literature that researchers need to consider.

**Relationships between investigators, interpreters and communities/caregivers:** Understanding power relationships between investigators, interpreters and communities is critical for participation to be truly voluntary; for communities to understand the programme and its implications (Hart and Tyrer, 2006); for children, families and communities to be comfortable with being involved (Laws and Mann, 2004); and for avoiding misunderstandings about the relationship between the programme and other humanitarian services or local authorities (Sumathipala et al., 2007).

**Relationships between different children:** Power relations also exist between children. Awareness and understanding of these relationships are necessary to avoid (a) some children within the research being silenced by their more powerful peers and, (b) assuming that certain children can appropriately represent their peers' perspectives and experiences in a given context (Hart and Tyrer, 2006; Morgan et al., 2002).

**Relationships between adults and children within communities:** Established and emerging perceptions of childhood, and the roles and expectations of children within different communities, need to be understood as part of the pre-research planning phase. Understanding prevailing power dynamics between adults and children (Beazley et al., 2009; Morrow, 2008; Coppock, 2014) is necessary to understand sensitivities, risks and issues related to accessing and engaging with child participants. As noted by Mann and Tolfree (2003):

*If the voices of children are the only ones being heard, then adults may feel threatened that their own experiences are not seen as valid. Some may feel threatened by this 'privileging' of children's views. (p.22)*



In resource-scarce environments, there is also a risk that adults may coerce children into participation based on perceived or actual benefits that might arise from the research. Alternately, adults may not wish for children to participate even if children themselves wish to participate. All cultures have particular perceptions of childhood and children, which may lead adults to see children's involvement in research as inappropriate. There may be a view that children lack knowledge or understanding that makes investigating their views unnecessary or even problematic. Adults may believe they know what children think, or what they should think. Therefore, it is important to investigate what underlies adults' wishes that children should not participate in research. These dynamics need to be understood, considered and adequately addressed in the design, consultation process, implementation and communication of the research and its findings in order to support informed and voluntary participation of children.

**Researchers' relationship with children:**

*Adults need to think about what they can do to support children – in terms of ensuring neutrality, transparency and trust.* (Hart and Tyrer, 2006, p.26)

Adult researchers enjoy a significant position of power in relation to children. Humanitarian settings may exacerbate this power differential. Ethical research means working to minimize such phenomena, and checking assumptions about childhood.. This would include ensuring opportunities to inform and meaningfully involve children in research on issues that are relevant to their lives, including those that may or may not overlap with those relevant to adults. Further, informing and gaining the support of children's parents or guardians and/or other key stakeholders is required. Finally, careful selection of research methods that are appropriate to the context, the research questions, and to children's own capacities, interests and time availability should be adopted (Alanen and Mayall, 2001; Punch, 2002; Christensen, 2004; Irwin, 2006).

**Researchers' relationship with communities:** Criticism has rightly been leveled at the conduct of research that is purely 'extractive': offering little or nothing to the participants and their wider community. Ideally evidence gathering should happen as part of an ongoing dialogue with a community and local organizations focused on finding solutions to the issues faced by those communities, including their children (Beazley et al., 2009; Feinstein and O'Kane, 2008b). Further, the social dynamics relating to age, ethnicity, class/caste, (dis)ability, and gender in any specific context need to be properly understood prior to evidence gathering. These considerations should help determine the selection of participants and other individuals to be consulted to obtain consent and support. Appropriate community engagement also requires reflection on the gender, background and age of the person(s) collecting data, the ways in which questions are framed, and how the research is implemented. As noted by the IASC AAP (2011), a commitment is required,

*[To e]nable affected populations to play an active role in the decision-making processes that affect them through the establishment of clear guidelines and practices to engage them appropriately and ensure that the most marginalised and affected are represented and have influence.*

The following case study explores notions of participation, voice and representation. It highlights the importance of practices that support appropriate representation of children's voices. In this example, the children themselves articulated the need for broad and fair representation within the research, resulting in positive institutional responses to the issue raised.

**Case Study: Inclusion and Representation Issues with Child Researchers in Uganda<sup>4</sup>**

From September 2006 to October 2008 Save the Children Norway supported children's participation in a thematic evaluation on children's participation in communities in times of armed conflict, post conflict and peace building in Bosnia-Herzegovina, Guatemala, Nepal, and Uganda. As part of the participatory research and evaluation process, in-country 'research groups' and 'advisory committees' were formed involving children and national researchers (adults). Members of the research group (and sometimes the advisory committee) were provided with opportunities to join capacity building workshops on participatory research to enhance their knowledge, confidence and skills in undertaking ethical and participatory research and evaluation.

**The ethical challenge:** In Uganda, four children's representatives (two girls and two boys) took part in the initial start-up workshop. In the process of establishing the adult-child research groups and advisory group in Uganda, an ethical challenge arose as to which children would have an opportunity to be part of these structures and the related capacity building workshops. During a Peace Club meeting children asked whether the same Club members who attended the last workshop would also attend the next workshop. One member remarked: "If the same members keep on going for workshops, then there is no need why we should stay as members in this club." The issue of representation was raised by almost all the clubs and associations involved in the thematic evaluation process.

**Choices made:** After consultations, it was agreed that different children would have a chance to attend each participatory research workshop to provide opportunities for a larger number of girls and boys to be actively involved in the participatory research and evaluation process. Since then, the "rotational system of representation" has been the mode of selecting children to participate in activities organized under the thematic evaluation.

The rotational system of representation works through:

- **Democratic elections:** Through a democratic process, children elect their own representatives each time for any activity.
- **Inclusive and ethical participation:** Children commit to an inclusive and ethical process. That is, equal numbers of boys and girls are involved, representing different age groups, ethnic/tribal backgrounds, abilities (including children living with disabilities), and educational backgrounds.
- **Peer sharing and learning:** Elected children have the responsibility to share knowledge and skills they have gained with peers in clubs and associations.

This system enabled the active participation of 603 children (225 females and 378 males). They included: in- and out-of-school boys and girls, children with disabilities, formerly abducted children, child mothers and orphans. Many of the children were living in camps of internally displaced people. Children also reported that '*children who went for workshops and trainings rolled out the knowledge gained to other children*' (Save the Children Norway and Save the Children in Uganda, 2008).

However, continuity was deemed important for the advisory committee, so rather than have rotating membership, it was decided to elect children's representatives. Nonetheless, rather than elect only a few children, 24 (12 girls and 12 boys) were elected onto the advisory committee, together with 6 adults representing the various local and international partners.

<sup>4</sup>This case study by Clare Feinstein and Claire O'Kane was included in Graham et al. (2013). The authors also extend appreciation to Dr. Kato Nkimba for his contributions to this case example from Uganda.

Understanding and reflecting on power relations in the design and implementation of research involving children in humanitarian settings is critical to understanding the potential for harms and benefits arising from the research itself. This will be explored in the next section.

## 4.5 Harms and benefits

### Key issues to consider

- Evaluating risks and benefits
- When to include children in research in these contexts
- Engaging children to understand, inform and reflect on risks
- Environmental safety and security
- Appropriate methods and implementation
- Taking photographs or videos

When assessing potential harms and benefits, the first ethical consideration is whether a particular research project involving children needs to be conducted in a humanitarian setting (Graham et al., 2013). In light of the potential risks of research involving children in humanitarian settings, more stringent frameworks for decision-making are required that place a greater emphasis on direct benefits and minimizing or mitigating harm (Sumathipala et al., 2007). The following are the key issues raised in the literature regarding harms and benefits that need to be considered for the ethical involvement of children in research in these settings.

**Evaluating risks and benefits:** International and other guidelines for the ethical conduct of research involving human subjects all note that consideration must be given to the immediate and longer term risks of people's participation in research programmes (CIOMS, 2002; The Belmont Report, 1979; Graham et al., 2013; Feinstein and O'Kane, 2008b). This entails consideration of the necessity of the research (Sumathipala et al., 2007), designing and enacting relevant protection protocols (Hart and Tyrer, 2006), and reflecting on the burdens of participation and how they can be avoided or minimized (Feinstein and O'Kane, 2008b).

At the same time, the research may and should produce benefits. Ideally, children participating in research should derive some benefit from participation, even if it is simply the satisfaction of improving the situation of other children. Sometimes the benefits may not be available to the child participants themselves, but the research may benefit children caught up in future humanitarian crises (Sumathipala et al., 2007). The following case study explores the ways in which the research process itself can provide benefits to children and communities in these settings.

**Case Study: Benefits of Research for Children and Young People: The 3M evaluation of child and youth participation in peacebuilding**

(McGill, O’Kane, Bista, Meslaoui, and Zingg, 2015)

In July 2014, the Global Partnership for Children and Youth in Peacebuilding initiated a multi-agency, multi-country evaluation in Colombia, Nepal, and the Democratic Republic of Congo (DRC) which included building the capacity of children and youth to meaningfully participate in evaluations.

The evaluation was primarily qualitative. A multi-method approach was applied, including Focus Group Discussions (FGDs) using participatory evaluation tools with different age groups, online mapping, interviews, drawing, stories and analysis of available secondary data. In particular, visual participatory evaluation tools including a Timeline, a before and after Body Map and other tools were adapted (Lansdown and O’Kane, 2014) and applied to help *“capture complex social change processes and illuminate interactions between interventions and the context”* (OECD, 2012, p.32).

The evaluation process consistently focused on capacity building and mentoring of youth and children as evaluators. This type of participatory evaluation involving children and youth as evaluators was new for the majority of stakeholders involved.

As a result, it was initially quite challenging for many of the stakeholders to understand the entire process, and in Nepal and the DRC, some children, youth, and adults expressed concerns about whether they would be able to implement the evaluation as planned. Initial National Capacity Building Workshops provided crucial opportunities to build the skills, knowledge, and confidence of Local Evaluation Team (LET) members. Furthermore, ongoing mentoring and support reduced concerns and increased child and youth confidence as evaluators.

Providing opportunities for children and youth to be part of planning, data collection, data analysis, and development of key messages and recommendations increased child and youth engagement, feelings of respect, and their sense of ownership of the findings.

Child and youth LET members expressed how they developed and strengthened their facilitation, communication, leadership, and evaluation skills, and gained knowledge to strengthen their peacebuilding initiatives.

As highlighted in the case study above, providing opportunities for children and youth to be part of each stage of the process can enhance the benefits of their engagement (Laws and Mann, 2004). Employing research methodologies in an appropriate and inclusive way that can directly benefit child participants adds support to the ethical justification for research with children in volatile contexts.

***When not to include children in research in these contexts:*** The benefits to involving children in research must be balanced against the risks of their involvement. Consideration must be given to a wide range of risks, especially if some are potentially serious, or if caregivers and/or powerful local players have not agreed to these activities. According to the International Rescue Committee, some circumstances make it ethically inappropriate to collect data from children (IRC, 2012a).

Their guidance on when to advocate against child participation is as follows:

- Where children's (or other's) safety will be put at risk
- Where basic care and support services are not available
- Where skilled interviewers are unavailable
- Where relevant and useful information can be gathered elsewhere (IRC, 2012a; WHO, 2007).

Risk assessments need to take into account both short-term and longer-term risks from the research. The case study below highlights the implications of changing community attitudes and social dynamics that may result from the research itself.

**Case Study: Children at Risk from Participatory Risk Reduction?** (See: Mitchell et al. 2010)

Children are increasingly being engaged in risk reduction work, particularly in the disaster risk reduction and climate change adaptation fields (Back et al. 2009). Empowerment of children to understand their vulnerabilities and to enhance their capacity – both to voice their concerns to decision makers and take action themselves – is crucial. Yet in taking action to reduce existing risks and adapt to changing risks, children's groups may directly challenge vested interests and power relations potentially exposing them to threat. These challenges were illustrated through direct action on risk reduction by children in the community of Petapa, El Salvador.

The River Sumpul forms the border between the study communities and Honduras, generating large flows during the wet season with the power to cause significant scouring and riverbank erosion. The children of the Petapa Emergency Committee identified the un-regulated extraction of rocks and stones from the river as a major risk, leading to increased erosion and vulnerability to flooding of houses near the river. Signs prohibiting extraction for personal use have since been erected with the agreement of the local leaders.

Buoyed by their previous activities and acting on the strength of their convictions, a number of children from the programme went to the river to protest the arrival of a lorry from outside the community intending to load stones from the river. They sat on top of the lorry until it agreed to leave. Although the lorry driver claimed this was for personal use, this collection had apparently been sanctioned by local authorities, revealing power relations central to the challenge of risk reduction.

While laudable in their convictions, the participation of children in risk reduction activities inadvertently exposed them to increased harm, particularly where challenging the underlying drivers of vulnerability required challenging underlying power relations and vested interests. Such possibilities need to be carefully monitored by facilitating agencies who may be in a strong position to mediate in such situations and thereby protect children from potential risk or danger.

**Engaging children to understand, inform and reflect on risks:** From the above case study it is difficult to ascertain whether the impact of challenging power dynamics within the research programme could have been foreseen and mitigated. However, as argued by Hart and Tyrer (2006), an important strategy to minimize risks to children in situations of conflict and post conflict is:

*Working together with children to help them analyze and plan the most safe and effective ways to influence key adults in positive ways. Remember to apply good practice in supporting children's participation which promotes the safety and protection of children. (p.26)*

While it is uncertain if prior reflection and analysis could have prevented the children in the above case study putting themselves at risk, participatory exercises reflecting on safe approaches to influence key adults may be a valuable tool to mitigate these risks.

**Environmental safety and security:** Any kind of field-based enquiry in the context of a humanitarian emergency entails heightened risk for all involved. In the context of children participating in research the literature clearly identified the need for available and accessible nearby spaces where it is possible to conduct research with children safely, privately and without raising suspicion (Hart and Tyrer, 2006). This requires knowledge of high risk areas that need to be avoided during research activities or using research locations that do not require children to use dangerous routes (Hart and Tyrer, 2006; UNICEF, nd). As noted by Hart and Tyrer (2006),

*... areas need to be avoided during research activities to avoid risk of danger to children such as landmines, child abduction or armed conflict. (p.25)*

While not directly related to children per se, organizations sending staff or engaging consultants also have a very specific duty of care to staff. A strategy for security requires, amongst other things, detailed knowledge of the context and of the potential sources of risk. In order to ensure the security of the programme team in the field, input should be sought from longstanding or respected actors doing similar work (INGO, NGO, etc.) to determine appropriate safety arrangements, necessary staff psychosocial support mechanisms and communication channels required for data collectors and investigators in the field (Social Research Association, nd).

**Appropriate methods and implementation:** As should be apparent from the case studies, no method per se is safer or more ethical for research involving children in humanitarian settings. It is the interplay between the method, the issue(s) it seeks to explore, the context and how the method is implemented that will determine potential harms and benefits, and the ethical issues that need to be reflected upon. As identified in the broader literature on involving children in research, methods should reflect the capacities of the children involved (Johnston, 2008; Morrow and Richards, 1996), their sensitivities and the means by which the research effort could potentially provide opportunities for recreation and self-expression (Akesson et al., 2014). These opportunities can be particularly valuable in the context of humanitarian crises – both during and after – where opportunities for children to express themselves are often limited.

However, as noted by Feinstein and O'Kane (2008) while opportunities for self-expression can be beneficial for children, their exact meanings must be checked with them, especially if there is a need to extrapolate from the mediums used (e.g. pictures, drama, ordering of objects, verbal responses). While this is necessary for the accuracy of research findings, there is also an ethical imperative for children's voices to be heard accurately so that consequent actions arising from findings are not



skewed by priorities and assumptions that in effect come from the researchers. Care is needed to ensure that written materials such as essays and diaries do not include incriminating information if they are to be publically available and/or if their security cannot be guaranteed.

***Taking photographs or videos:*** When using creative methodologies to involve children in research, particular care needs to be taken with photography or videos (Mann and Tolfree, 2003), especially in politically and socially volatile settings, such as humanitarian settings. Prior consultations should always be undertaken with those best able to assess the political, social and cultural ramifications of taking or disseminating photographs in these contexts. Clear discussions are needed with children regarding permission from those portrayed in photographs or videos, and the potential dangers of these portrayals (UNICEF, 2015).

## 4.6 Informed consent and capacities of participants

### Key issues to consider

- Challenges of informed consent with unaccompanied minors
- Determining competency to consent
- Ensuring ongoing consent

***Challenges of informed consent with unaccompanied minors:*** Informed consent is an integral part of respecting participants in any research activity (Alderson and Morrow, 2004). While little research has specifically interrogated the issue of consent/assent of children involved in research in humanitarian settings, it is likely to be complicated by the displacement, loss or separation from parents/caregivers and by the significant challenge of ascertaining competencies and agency of children given changing roles and exposure to extreme circumstances. Therefore delegation of authority for informed consent will need to be clearly determined at the outset, particularly if national laws pertaining to the need for guardian consent to research are in place.

***Determining competency to consent:*** In light of the fact that unaccompanied children, and particularly older children may have sufficient competency to understand the research and to provide informed consent, appropriate methods for obtaining consent from children (and from any identified relevant guardians if their consent is required) need to be developed. This includes reflecting on their circumstances, capabilities and cultural attitudes to the signing of documents (Mann and Tolfree, 2003; Dorn et al., 1995). Further, staff need to be trained to ascertain children's ability to give informed consent, particularly where no primary caregiver or guardian is available (Ní Raghallaigh and Gilligan, 2013; Sumathipala et al., 2007), with consideration given to the creation or adaption of relevant competence assessment tools that can reflect the context and timing (Hein et al., 2012). This need for appropriate and valid consent is relevant in both the gathering of information and the collection of biological samples (Sumathipala et al., 2007).

***Ensuring ongoing consent:*** A further issue highlighted in the literature is the need for informed consent to be ongoing and not a one-off activity (Morrow, 2009; Ní Raghallaigh and Gilligan, 2013).

This is particularly relevant to humanitarian contexts given the volatility of the settings and the circumstances. Children should have opportunities to withdraw from a research project at any point if they change their minds. Practical means of doing so should be provided, which can be difficult given the power dynamics discussed earlier. Interviewers should be trained to identify non-verbal cues that children no longer wish to participate. The following case study reflects on the use of ongoing and inclusive consent processes.

**Case Study: Tailoring Informed Consent to the Sensitivities of Children: Ongoing consent for unaccompanied migrants in Ireland (Ní Raghallaigh and Gilligan, 2013)**

Exploring the experiences of unaccompanied adolescents seeking asylum in Ireland, this project was designed to include participant observation in a hostel as well as interviews with participants. Steps were taken to ensure that informed consent was rigorously supported and voluntarily provided by all living in the hostel.

Informed consent was approached in two parts. Firstly, all residents in the hostel were asked whether or not they agreed to the researcher being present in the hostel. Presence in the hostel would involve the researcher observing their lives there and having informal conversations with the young people. Secondly, all the residents were asked if they wished to be participants in the study. The young people were informed that participation could involve allowing the researcher to take field notes in relation to them and/or participating in an interview. They were informed that the researcher would not take notes in relation to anyone who did not wish to be a participant. All residents gave verbal consent to the researcher being present in the hostel. A majority gave written consent to their participation in the research.

Informed consent is increasingly recognised as a process which needs to be revisited during a project. In this project, the researcher regularly asked residents in the hostel about whether their consent had changed. Some residents who had originally not consented to participation changed their mind and consented to be interviewed. Others who had consented to both the researcher's presence and to participation subsequently decided that they did not want to be interviewed. All residents continued to state that they were happy with the researcher being present in the hostel.

The case study above, whilst not set in a humanitarian context, addresses issues relating to unaccompanied children, co-location of children in contexts where privacy may be limited and in circumstances where populations are transitory. All of these conditions are likely to be present in humanitarian settings and indeed most participants in the above study are likely to have sought asylum consequent to humanitarian crises in their country of origin. Within this study, the ethical issues arising are consequent not only to traditional data collection through interviews but also as a result of observation-based research, requiring that consent be ongoing and obtained from all those present and not just those choosing to participate in the study. In humanitarian settings, consent should be sought from those impacted by the presence of the researchers within their physical spaces, not just from participating children themselves. Finally, this consent should be ongoing to account for changes to conditions and environments in which the research may take place.



## 4.7 Privacy and confidentiality

### Key issues to consider

- Culture, age and context appropriate approaches to privacy
- Data confidentiality and security

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**Culture, age and context appropriate approaches to privacy:** Cultural, individual and environmental factors can and do significantly impact on notions of privacy. Further, they can impact the capacity of the researcher to protect participants' privacy irrespective of the nature of the data collection (i.e. surveys, interviews, focus groups or participatory activities) (Morrow, 2009). However, in humanitarian settings the need for privacy can be heightened not only due to greater political sensitivities and tensions but also by virtue of living conditions (Hart and Tyrer, 2006). As is the case for all research, the privacy of child participants needs to be clearly thought out (Sumathipala et al., 2007), taking into account issues such as:

- Age and gender (Alderson and Morrow, 2004)
- The potential need for reassurance brought by the physical presence or proximity of a trusted adult (Shaw et al., 2011)
- Cultural norms (Jenson, 2015)
- The capacity of the child to freely participate in the presence of family and guardians (Graham et al., 2013)
- The methods and approaches adopted to protect privacy without raising suspicion (Hart and Tyrer, 2006)
- The safety of all parties (WHO, 2007) and protection against possible retaliation due to participation.

**Data confidentiality and security:** Standard principles of confidentiality apply to research programmes (UNICEF, 2014, Boddy et al., nd). In humanitarian contexts, however, the imperative is stronger given the volatility, instability and increased danger of the circumstances (Hart and Tyrer, 2006). Anonymity in data, quotes and case studies prior to publication or dissemination is required to ensure that children, communities and specific locations are not identifiable (unless participants make a specific request to be identified during an appropriately rigorous informed consent process) and the confidentiality of participants' data is maintained (CP MERG, 2012; Graham et al. 2013; Feinstein and O'Kane, 2008b; WHO 2011). Further, higher standards and increased security measures are needed in the storage and transfer of data (Sumathipala et al., 2007).

*As humanitarian data is aggregated and made public, the chances for re-identification of individuals and groups increase at an unknown rate. This phenomenon, known as the mosaic effect, is widely recognized but little understood. There is little understanding of the dangers that shared anonymous data would pose in a humanitarian context, where data may be limited, but the potential damage of re-identification would be quite extreme. (Bergtora Sandvik et al., 2014)*

A good understanding of security options is requisite not only for physical storage but also for technological storage, with consideration of the possibility and need for encryption and password protection. Methods for transferring and sharing data should ensure that the confidentiality of data pertaining to children, their communities and the organization(s) collecting the data is not compromised (Crowe, 2013) and that appropriate means and timing for the destruction of hard copies of data/samples is determined. New and emerging technologies and innovation in research associated with big and open data have the potential power to do tremendous good for children in humanitarian settings e.g. the UNICEF-developed RapidFTR.<sup>5</sup> However, there is a need to appropriately balance the risks and benefits for children of such approaches, to not be seduced by the technology and to seek independent technical advice and support when considering big/open data tools and approaches.

#### 4.8 Payment, compensation, ancillary services and reciprocity

##### Key issues to consider

- Meeting need versus payment and compensation
- Consulting humanitarian actors on the need or approach to compensation
- Opportunity cost of children's participation
- Equity, voluntariness and avoiding coercion
- Reciprocity

**Meeting need versus payment and compensation:** Payment or compensation for child participants is likely to present significant ethical challenges in environments of acute scarcity of resources which frequently define humanitarian settings (CP MERG, 2012). Providing payment, compensation or ancillary services to participants and not to the broader community can create or exacerbate pre-existing tensions. This is particularly problematic with respect to fulfillment of one of the Core Humanitarian Standards which demands impartiality, requiring that humanitarian action be carried out on the basis of need alone (Humanitarian Accountability Partnership, 2014). While researchers may not be humanitarian actors per se, they frequently are part of, or feed into, humanitarian responses.

**Consulting humanitarian actors on the need for or approach to compensation:** Relevant guidance from the field of ethical research relating to violence against children highlights that consultation with other humanitarian actors is required to determine the need and nature of any compensation to be provided (Laws and Mann, 2004).

*[Participants] may believe that participating in research originating abroad may improve their chances of accessing food or other overseas aid. (O'Mathuna, 2010, p.73)*

<sup>5</sup> "[Ftr is a mobile] application specifically designed to streamline and speed up Family Tracing and Reunification efforts both in the immediate aftermath of a crisis and during ongoing recovery efforts."

Both knowledge of any local child labour laws and prior consultation with humanitarian actors and/or others doing similar work in the same area will help determine a number of critical issues. These issues include the need for and nature of compensation or payment to children participating in research, and the best approach to its provision (if, when and how) and any implications for community relations. Importantly, consultations will help clarify the expectations that may be present or that may arise regarding provision of goods and services.

*Make sure that you address issues of material or symbolic rewards for participation in a transparent and fair way and that you manage all expectations in this respect...*

(Feinstein and O’Kane, 2008b, p.23)

The following case study highlights the importance of contextual factors in the determination of payment, compensation or ancillary service provision.

### **Case Study: Compensation and Payment of Youth and Child Evaluators**

(see McGill et al., 2015)

In the 3M Evaluation of Child and Youth Participation in Peacebuilding programme budgets were provided to the Country Steering Team to support a participatory evaluation process. Budgetary and material support to the Local Evaluation Teams (LETs) was crucial for implementing planned evaluation activities.

Complex ethical dilemmas regarding payment or non-payment of LET members were carefully considered by the Global Evaluators, members of the Global Partnership Steering Teams, and Country Partnership Steering Teams. In Colombia and Nepal, the LET Coordinators (experienced youth) were paid a monthly wage in line with their additional responsibilities for coordination, support to LET members, transcription, and data storage. These paid positions significantly increased the efficiency and effectiveness of the LETs. In contrast, miscommunication in the Democratic Republic of Congo (DRC) context resulted in a lack of payment to LET Coordinators which contributed to reduced motivation and delays in data collection and transcription.

Other LET members from all three countries were volunteers and were provided with mobile phone credit, transport and food allowances, as well as certificates recognising the skills and knowledge they gained as evaluators. National laws regarding child labour were identified and respected. Children’s best interests and evolving capacities were carefully considered, and sincere efforts were made to support planning with and by child and youth evaluators to ensure that work plans were realistic considering their roles as volunteers, while also considering their existing responsibilities to study, support their households, enjoy leisure time, etc. Each LET was also provided with sufficient material such as flipchart, pens, coloured cards, etc. to undertake the evaluation activities, and a camera was either purchased or borrowed for the duration of the evaluation. Refreshments and snacks were also provided to participants during activities.

In the DRC some of the youth and child evaluators were reluctant to engage in the evaluation process without financial remuneration. They felt that they were requested to do too much work within a short period of time and thus payment should have been provided. In contrast, in Nepal and Colombia, child and youth evaluators were very positive about the opportunities offered to them as volunteer evaluators to undertake Focus Group Discussions in their local areas and in neighbouring communities. They recognised it as an important learning opportunity that enhanced their personal development and provided opportunities for them to strengthen their peacebuilding initiatives; children and youth highlighted the knowledge and evaluation methodologies acquired during the evaluation as the main and best compensation.

**Opportunity cost of children's participation:** The variability in financial remuneration in the differing countries noted in the above case study clearly highlights the importance of context when determining an ethical approach to payment to and compensation of children, particularly in research where children are undertaking roles for which adults are paid. In the above example, cultural norms, opportunities for skills development, resource scarcity, employment opportunities, the economic costs of participation and local child labour laws were all factors impacting on the ethical determination of payment and compensation for participation in research. These factors would need to be considered within the planning phases of research involving children.

**Equity, voluntariness and avoiding coercion:** The resource scarcity often found in humanitarian crises is likely to require greater reflection on (i) issues of equity and the perception of equity within the communities in which the research is undertaken, (ii) risks of inadvertent coercion and bribery resulting from payment or compensation (whether direct or indirect through pressure from parents or guardians for children to participate), and (iii) maintaining the humanitarian imperative of responding to need and the risk of potentially privileging participants over equally deserving peers.

*Compensation for participants raises related ethical concerns. Again, the issue is not unique to disaster research ethics, except in that the extensive needs of potential participants may leave them more susceptible to undue inducements.*

*(O'Mathuna, 2010, p.71)*

**Reciprocity:** Related to compensation and payment is the notion of reciprocity. This concept holds true for all ethical research involving children, but is particularly important within the context of humanitarian settings. When selecting child participants in situations where there is an acute scarcity of resources, reciprocity should be understood and defined in a way that includes non-material benefits or goes beyond granting privileged access to services. As noted previously, well-designed research can provide a platform for building skills, for respite and play and for providing a heightened sense of self-respect and self-esteem (Hart and Tyrer, 2006; Gibbs et al., 2013; Feinstein and O'Kane, 2008b; Laws and Mann, 2003). Well-designed research could also incorporate psychosocial elements and allow for ethical forms of compensation that are not based on payment, provision of goods or privileged access to limited services.

### **Case Study: Responding to Needs Identified in Studies**

In the previously discussed study on Child Fosterage and Child Domestic Work in Haiti (Cayemittes et al., 2014), researchers and enumerators referred several children who were not in school to different educational facilities. Between 10 and 15 of these children were later assisted by community workers into educational arrangements. In this way the research programme was able to respond to children's needs and the priorities identified in the data collection process, and, despite it being outside the purview of the research itself, supported them in addressing their identified need to go to school.

## 4.9 Communication of results

### Key issues to consider

- Reviewing reports prior to dissemination
  - Triangulation and feedback into communities
  - Using research for change
- 

The final issue noted in the literature regarding the ethics of involving children in research and particularly as relates to humanitarian settings is the ethical dissemination and communication of findings (Graham et al., 2013).

**Reviewing reports prior to dissemination:** In the context of instability, conflict, political sensitivity and population vulnerability, ethical research requires a thorough review of reports and products prior to publication or dissemination so that children and other participants are not identifiable (unless participants give explicit permission to be identified during an appropriately rigorous informed consent process) (CP MERG, 2012; Sumathipala et al., 2007). This is necessary to avoid any possible retaliation for participation or opinions.

**Triangulation and feedback into communities:** Consistent with the notion of reciprocity identified above, ethical research involving children in these contexts should, also, where appropriate, be accessible to the communities in which the research was undertaken (Feinstein and O’Kane, 2008b). This can include the production of child-friendly findings reports where it is possible and safe to do so (Collision and O’Kane, 2009).

**Using research for change:** Finally and importantly, the literature notes that ethical research in these environments should increase the likelihood that findings will be used to secure positive changes for children (Ennew and Plateu, 2004) within the humanitarian response phase and beyond. The case study at the end of the last section shows one way this can be done. This aspect requires consideration within the planning phase to ensure appropriate communication, and uptake strategies are included (Ennew and Plateu, 2004).

## 5. CONCLUSION

Reflecting on the UNICEF *Ethics Procedure* it should be apparent that the principles remain relevant within humanitarian settings. Notions of respect, benefits and justice, are all reflected in the issues for consideration identified in the literature. However the application of these principles is, in many respects, more complex. The ethics of research in humanitarian settings involving children can be considered a very specific case defined by heightened risk, resource scarcity, instability, mobile or transient populations and often time sensitivity where minimising harm becomes more difficult and outcomes more unpredictable. The most obvious difference is that humanitarian settings result in more extreme conditions that can and should be explicitly accounted for in the content, method and environments in which research with children takes place. Reflection on the ethical principles and issues by all involved in such research is therefore crucial throughout these activities, especially during planning and consultation.

As highlighted throughout the paper, the ethical issues involved in undertaking research involving children in humanitarian contexts are incredibly complex and strongly determined by historical, cultural, environmental, social and political factors that define these circumstances and the child populations within them. It is ultimately careful consideration and consultation regarding the specificities of the particular humanitarian setting that should determine planning, coordination, protocols and actions to address predictable ethical issues and mitigate against unforeseen ethical issues. This includes improving researcher reflexivity and reflection, acknowledging the diversity of children and their experiences, and understanding the implications of ensuring inclusive or targeted and appropriately tailored research within these complex contexts.

This paper has demonstrated that there will be instances where involving children in research in humanitarian contexts can clearly not be justified; for instance where the risk of harm is too high or where other pre-existing data can be used. However, when involving children in research is unlikely to place the child at severe risk, or potential risks can be mitigated, and where the benefits to children are clear, ethical approaches need to be tailored to the lives and realities of the children involved. This paper provides a basic starting point for organizations considering research involving children in these environments to determine whether they have the resources, systems and capabilities to truly listen to them, to act on findings and to do so with appropriate sensitivity and respect.

With these issues in mind, it is hoped that the high risk aversion that is frequently used as a justification for exclusion of children in these contexts is counterbalanced by an understanding of potential approaches to support their ethical participation in research and the benefits of doing so. Finally, it is hoped that this working paper may provide the impetus for increasing the documentation and sharing of knowledge, guidance and practical advice on the specific ethical implications of undertaking research involving children in humanitarian contexts.



## REFERENCES

- Akesson, B., D'Amico, M., Denov, M., and Khan, F. (2014). "Stepping back" as Researchers: Addressing ethics in arts-based approaches to working with war-affected children in school and community settings, *Educational Research for Social Change*, 3(1), pp.75 – 89.
- Alanen, L. and Mayall, B., (2001). *Conceptualizing Child–adult Relations*. London: Routledge
- Alderson, P., & Morrow, V. (2004). *Ethics, Social Research and Consulting with Children and Young People*. Ilford, Barnados.
- Alderson, P. (1995). *Listening to Children, Children, Ethics and Social Research*, Barkingside, Barnados.
- Alderson, P., and Morrow, V. (2004). *Ethics, Social Research and Consulting with Children*, Barkingside Barnados, available at:  
[www.preventionweb.net/files/12085\\_ChildLedDRRTakingStock1.pdf](http://www.preventionweb.net/files/12085_ChildLedDRRTakingStock1.pdf)
- Back, E., Cameron, C. and Tanner T.M. (2009). *Children and Disaster Risk Reduction: Taking stock and moving forward*. Children in a Changing Climate Research Report, Brighton, UK.
- Beazley, H., Bessell, S., Ennew, J., and Waterson, R. (2009). The Right to Be Properly Researched: Research with children in a messy, real world, *Children's Geographies*, 7(4): 365-378.
- The Belmont Report (1979). *Ethical Principles and Guidelines for the Protection of Human Subjects of Research*. Bethesda, The Commission, Academy of Social Sciences.
- Bergtora Sandvik, K., Wilson, C., Karlsrud, J. (2014). *A Humanitarian Technology Policy Agenda for 2016*, June 30, 2014, Humanitarian Academy at Harvard.  
<http://www.atha.se/content/humanitarian-technology-policy-agenda-2016>
- Boddy, J., Neumann, T., Jennings, S., Morrow, V., Alderson, P., Rees, R., and Gibson, W. (nd) *The Research Ethics Guidebook: A Resource for Social Scientists, Economic and Social Research Council*, <http://www.ethicsguidebook.ac.uk/>, accessed 9/12/2015.
- Cahill, H., Beadle, S., Mitch, J., Coffey, J. and Crofts, J. (2010). *Adolescents in Emergencies*, background paper for the Adolescents in Emergencies Regional Workshop: Asia Pacific Bangkok, 27-29 July, 2010, University of Melbourne.
- Cayemittes, M., Hatløy, A., Lunde, H., Pedersen, J., Sommerfelt, T. and Spraos, H. (2014). *Child Fosterage and Domestic Work*, FAFO Research Foundation, Oslo. CP MERG - Child Protection Monitoring and Evaluation Research Group (2012). *Ethical Principles, Dilemmas and Risks in Collecting Data on Violence against Children: A Review of Available Literature*, Statistics and Monitoring Section/Division of Policy and Strategy, UNICEF, New York.
- Christensen, P. 2004. Children's Participation in Ethnographic Research: Issues of power and representation, *Children and Society*, 18, 165–176.
- Clarke, M, Allen, C, Archer, F, Wong, D, Eriksson, A and Puri, J. (2014). *What Evidence is Available and What is Required in Humanitarian and Transition Assistance?* 3ie, Scoping Paper New Delhi: International Initiative for Impact Evaluation (3ie).  
[http://www.3ieimpact.org/media/filer\\_public/2014/12/17/3ie\\_scoping\\_paper\\_1-humanitarian-top.pdf](http://www.3ieimpact.org/media/filer_public/2014/12/17/3ie_scoping_paper_1-humanitarian-top.pdf)

- Collision, D. and O’Kane, C. (2009). Save the Children in Myanmar Case Study on Children's Participation in Evaluations. 'Young voices, big impressions': Children's feedback on our post-Nargis response, Save the Children Myanmar.  
<http://resourcecentre.savethechildren.se/library/save-children-myanmar-case-study-childrens-participation-evaluations-young-voices-big>.
- Connolly, P., (2008). Race, Gender and Critical Reflexivity in Research with Young Children, in *Research with Children: Perspectives and Practice*, 2nd edition (edited by Pia Christensen and Allison James), Routledge, pp. 173-188.
- Coppock, V. (2014). Perspectives from within the ‘New Sociology of Childhood’ and Childhood Studies, *Development of Recommendations for the Assessment of Adolescents’ Competence in Clinical Care*, Brocher Workshop, 17-19th June.
- CIOMS – Council for International Organizations of Medical Sciences & World Health Organization (2002). International Ethical Guidelines for Biomedical Research Involving Human Subjects, Geneva, CIOMS. (1978).
- Crowe, A., (2013). A Paucity of Privacy: Humanitarian, development organisations need beneficiary data protection policies, Privacy International, <https://www.privacyinternational.org/node/240>
- Devries, K., Child, J., Elbourne, D., Naker, D. and Heise, L. (2015). “I never expected that it would happen, coming to ask me such questions”: Ethical aspects of asking children about violence in resource poor settings, *Trials*, (16)516. <http://www.trialsjournal.com/content/pdf/s13063-015-1004-7.pdf>
- Dorn, L., Susman, E. and Fletcher, L. (1995). Informed Consent in Children and Adolescents: Age, Maturation and Psychological State, *Journal of Adolescent Health*, 16 (3): 185-190.
- Ennew, J. and Plateau, D. P. (2004). How to Research the Physical and Emotional Punishment of Children, Save the Children, Southeast, East Asia and Pacific Region,  
<http://resourcecentre.savethechildren.se/sites/default/files/documents/3207.pdf>.
- Feinstein, C. and O’Kane, C. (2008a). Ethical Guidelines for Ethical, Meaningful and Inclusive Children’s Participation Practice, Save the Children, Norway,  
<http://childethics.com/wp-content/uploads/2013/09/Feinstein-OKane-2008.pdf>
- Feinstein, C. and O’Kane C. (2008b). Global Report: Adults War and Young Generations Peace: Children’s participation in armed conflict, post conflict and peace building, Save the Children Norway.
- Ford, N., Mills, E.J., Zachariah, R. and Upshur, R. (2009). Ethics of Conducting Research in Conflict Settings. *Conflict and Health*, 3 (7), pp. 1-9.
- Gibbs, L., Mutch, C., O’Connor, P. and MacDougall, C. (2013). Research with, by, for and about Children: Lessons from disaster contexts, *Global Studies of Childhood*, 3:2,  
[http://www.worlds.co.uk/pdf/validate.asp?j=gsch&vol=3&issue=2&year=2013&article=4\\_Gibbs\\_GSCH\\_3\\_2\\_web](http://www.worlds.co.uk/pdf/validate.asp?j=gsch&vol=3&issue=2&year=2013&article=4_Gibbs_GSCH_3_2_web)
- Graham, A., Powell, M., Taylor, N., Anderson, D. and Fitzgerald, R. (2013). *Ethical Research Involving Children*, UNICEF Office of Research – Innocenti.



- Hart, J., and Tyrer, B. (2006). Research with Children Living in Situations of Armed Conflict: concepts, ethics and methods, *Refugee Studies Centre Working Paper* No 30, Oxford.
- Haynes, K. and Tanner, T.M. (2015). Empowering youth and Strengthening Resilience: Child-centred participatory video as a tool for climate change adaptation and disaster risk reduction, *Children's Geographies* 13(3): 357-371.  
[www.tandfonline.com/doi/pdf/10.1080/14733285.2013.848599](http://www.tandfonline.com/doi/pdf/10.1080/14733285.2013.848599)
- Hein, I., Troost, P., Lindeboom, R., De Vries, M., Zwaan, M. and Lindauer, R. (2012). Assessing Children's Competence to Consent in Research by a Standardized Tool: A validity study, *BMC Pediatrics*, 12. <http://www.biomedcentral.com/1471-2431/12/156>
- Humanitarian Accountability Partnership (2014). The Core Humanitarian Standard on Quality and Accountability. <http://www.corehumanitarianstandard.org/the-standard>
- IASC AAP – Inter-Agency Standing Committee (IASC) Task Force on Accountability to Affected Populations (AAP) (2011). The five Commitments to Accountability to Affected Populations. <https://interagencystandingcommittee.org/accountability-affected-people>
- IASC AAP – Inter Agency Standing Committee on Accountability to Affected Populations (2015). Introduction to Humanitarian Action: A brief guide for resident coordinators. [https://interagencystandingcommittee.org/system/files/rc\\_guide\\_31\\_october\\_2015\\_webversion\\_final.pdf](https://interagencystandingcommittee.org/system/files/rc_guide_31_october_2015_webversion_final.pdf)
- IRC – International Rescue Committee (2012a). Caring for Child Survivors of Sexual Abuse: Guidelines for health and psychosocial service. [http://www.unicef.org/pacificislands/IRC\\_CCSGuide\\_FullGuide\\_lowres.pdf](http://www.unicef.org/pacificislands/IRC_CCSGuide_FullGuide_lowres.pdf), p.69
- IRC – International Rescue Committee (2012b). GBV Emergency Response & Preparedness Training. <http://gbvresponders.org/wp-content/uploads/2014/04/2-GBV-ERP-Training-PPT-GBV-Rapid-Assessments.pdf>
- Jenson, L., (Ed) (2015). *The Oxford Handbook of Human Development and Culture: An interdisciplinary perspective*, Oxford: Oxford University Press.
- Johnston, J., (2008). Methods, Tools and Instruments for Use with Children, *Young Lives Technical Note*, No. 11, Oxford.
- Lansdown, G. (2005). The Evolving Capacities of the Child, *Innocenti Insight*, UNICEF Innocenti Research Centre, Florence.
- Lansdown, G. and O'Kane, C. (2014). A Toolkit for Monitoring and Evaluating Children's Participation, Save the Children, Plan International, Concerned for Working Children, World Vision and UNICEF, London: Save the Children.
- Laws, S. and Mann, G. (2004). So You Want to Involve Children in Research? A toolkit supporting children's meaningful and ethical participation in research relating to violence against children, Save the Children, Sweden.
- Mann, G. and Tolfree, D. (2003). Children's Participation in Research: Reflections from the care and protection of separated children in emergencies project, Save the Children Sweden, Stockholm.

- McGill, M., O’Kane, C., Bista, B., Meslaoui, N. and Zingg, S. (2015). Evaluation of Child and Youth Participation in Peacebuilding: Nepal, Eastern Democratic Republic of Congo, Colombia, Oslo: Global Partnership for Children and Youth in Peacebuilding.
- Mitchell, T., Tanner, T.M. and Haynes, K. (2009). Children as Agents of Change for Disaster Risk Reduction: Lessons from El Salvador and the Philippines, Children in a Changing Climate, *Working Paper 1*, Brighton: Institute for Development Studies.
- Morgan, M., Gibbs, S., Maxwell, K., Britten, N. (2002). Hearing Children's Voices: Methodological issues in conducting focus groups with children aged 7-11 years, 2(1), pp.5-20.
- Morrow, V. (2008). Ethical Dilemmas in Research with Children and Young People about Their Social Environments. *Children’s Geographies* 6, 49–61.
- Morrow, V., (2009). The Ethics of Social Research with Children and Families in Young Lives: Practical experiences, *Young Lives Working Paper No.53*, Oxford.
- Morrow, V. and M. Richards (1996). The Ethics of Social Research with Children: An overview, *Children and Society*, Vol. 10: 90-105.
- National Research Council (2002). Research Ethics in Complex Humanitarian Emergencies: Summary of a Workshop. Holly Reed, Rapporteur, Roundtable on the Demography of Forced Migration, Committee on Population, Washington, DC: National Academy Press.
- Ní Raghallaigh, M. and Gilligan, R. (2013). Case Study 12: Obtaining informed and voluntary consent in a group context, in *Ethical Research Involving Children*, eds. Graham, A., Powell, M., Taylor, N., Anderson, D. and Fitzgerald, R., Florence, Italy: UNICEF Office of Research – Innocenti, pp. 138–141.
- O’Mathuna, D. P. (2010). Conducting Research in the Aftermath of Disasters: Ethical considerations, *Journal of Evidence-Based Medicine*, 3 (2), pp. 65–75.
- OECD (2012). Evaluating peacebuilding activities in settings of conflict and fragility: Improved learning for results. *DAC guidelines and reference series*, OECD publishing.
- Punch, S., 2002. Research with Children: The same or different from research adults? *Childhood*, 9 (3), 321–341.
- Putzel, J. and John, J. (2012). Meeting the Challenges of Crisis States, Crisis States Research Centre Report, Crisis States Research Centre, LSE, London.  
<http://www.lse.ac.uk/internationalDevelopment/research/crisisStates/download/finalreport/Meeting-the-Challenges-Executive-Summary.pdf>
- Save the Children (2014). *A Toolkit for Monitoring and Evaluating Children’s Participation*. Save the Children, Plan International, Concerned for Working Children, World Vision and UNICEF, eds. G. Lansdown and C. O’Kane, London: Save the Children.
- Shaw, C., Brady, L.-M. and Davey, C. (2011). Guidelines for Research with Children and Young People. National Children’s Bureau.  
<https://www.nfer.ac.uk/nfer/schools/developing-young-researchers/NCBguidelines.pdf>

- Social Research Association (nd). A Code of Practice for the Safety of Social Researchers, SRA, London, [http://the-sra.org.uk/wp-content/uploads/safety\\_code\\_of\\_practice.pdf](http://the-sra.org.uk/wp-content/uploads/safety_code_of_practice.pdf)
- Sumathipala, A., Jafarey, A., De Castro, L., Ahmad, A., Marcer, D., Srinivasan, S., Kumar, N.K., Sutaryo, S., Bhan, A., Wadeyaratne, D., Beneragama, S., Jayasekera, C., Edirisingha, S., Siriwardhana, C. and Siribaddana, S. (2007). *The Draft Statement/Guidelines for Disaster Research, Working Group on Disaster Research and Ethics*.  
<https://globalhealthtrials.tghn.org/articles/draft-statementguidelines-disaster-research/>
- Tanner, T.M. (2010). Shifting the Narrative: Child-led Responses to Climate Change and Disasters in El Salvador and the Philippines, *Children and Society* 24: 339–51.
- Tanner, T.M., Garcia, M., Lazcano, J., Molina, F., Molina, G., Rodríguez, G., Tribunalo, B. and Seballos, F. (2009). Children's Participation in Community-based Disaster Risk Reduction and Adaptation to Climate Change, *Participatory Learning and Action* 60: 54–64.
- The Sphere Project (2011). The Sphere Handbook: Humanitarian Charter and Minimum Standards in Humanitarian Response, <http://www.sphereproject.org/resources/download-publications/?search=1&keywords=&language=English&category=22>
- UNICEF (2015). UNICEF Procedure for Ethical Standards in Research, Evaluation and Data Collection and Analysis, UNICEF Office of Research – Innocenti, Florence.
- UNICEF (2015). *UNICEF Promoting Child Rights: Ethics of representation, 8 quick steps for ethical imagery*, (internal document).  
<https://unicef.sharepoint.com/teams/DOC/DigitalLabs/SitePages/Multimedia%20Guidance.aspx>
- UNICEF (nd). Emergency Field Handbook: A guide for field staff.  
[http://www.unicef.org/lac/emergency\\_handbook.pdf](http://www.unicef.org/lac/emergency_handbook.pdf)
- WHO – World Health Organization (2007). WHO Ethical and Safety Recommendations for Researching, Documenting and Monitoring Sexual Violence in Emergencies, WHO.  
[www.who.int/gender/documents/OMS\\_Ethics&Safety10Aug07.pdf](http://www.who.int/gender/documents/OMS_Ethics&Safety10Aug07.pdf)
- WHO – World Health Organization (2011). Ethical and safety guidelines for sexual and reproductive health research and data collection with adolescents, Geneva: World Health Organization (WHO), Department of Reproductive Health and Research.
- Zwi, A. and N. Grove (2006). Researching with Children in Conflict-Affected Settings, *Humanitarian Exchange*, 34.

## APPENDIX 1

## QUESTIONS FOR REFLECTION ON THE ETHICAL INVOLVEMENT OF CHILDREN IN EVIDENCE GENERATION IN HUMANITARIAN SETTINGS (SUMMARIES FROM THE LITERATURE)

ISSUE AND QUESTION	POSSIBLE RESPONSES
<p><b>Institutional capacity and will</b></p> <p><b>Organizational ability to listen and respond to children</b></p> <p>Is there organizational will to truly listen to children and respond to their priorities if they are not in line with, or challenge, those of the organization or potential funders?</p>	<ul style="list-style-type: none"> <li>Consider whether to undertake evidence generation involving children if there is little organizational will and capacity to listen and respond to children's priorities. Consider alternate data sources.</li> <li>Ask questions that are more directive and specific to the issue you are interested in and be clear in the findings/final reports of the limitations of the evidence generation.</li> <li>Do prior research to understand what expectations children and parents may hold with respect to what will be done with the findings and be absolutely clear on what can or can not be changed.</li> </ul> <p><b>Resources: Principles of good practice of humanitarian donorship</b></p> <p><a href="http://www.ghdinitiative.org/ghd/gns/principles-good-practice-of-ghd/principles-good-practice-ghd.html">http://www.ghdinitiative.org/ghd/gns/principles-good-practice-of-ghd/principles-good-practice-ghd.html</a></p>
<p><b>Background, training and capacities of staff:</b></p> <p>Do staff have the experience, knowledge and competency to work with children in these contexts?</p>	<ul style="list-style-type: none"> <li>Undertake background checks on staff wherever possible, even if this is through an informal (but rigorous) process.</li> <li>Hire or use staff that previously have undertaken research, evaluations or data collection involving children, and, if possible those who have done this in humanitarian contexts.</li> <li>Undertake an assessment of the competencies and sensitivities of data collectors prior to field work.</li> <li>Ensure appropriate training on ethical approaches to working with children is provided to all staff involved in data collection.</li> </ul> <p><b>Resources: Selection and Training of Fieldworkers</b></p> <p><a href="http://www.younglives.org.uk/publications/TN/selection-induction-supervisors-fieldwork-peru/tn24_selection-and-training-of-fieldworkers">http://www.younglives.org.uk/publications/TN/selection-induction-supervisors-fieldwork-peru/tn24_selection-and-training-of-fieldworkers</a></p> <p><b>Communicating with Child Survivors Attitude and Communication Tools found in the Caring for Child Survivors of Sexual Abuse: Guidelines for health and psychosocial service providers in humanitarian settings by the International Rescue Committee</b></p> <p><a href="http://gbvresponders.org/response/caring-child-survivors">http://gbvresponders.org/response/caring-child-survivors</a></p>
<p><b>Dealing with unanticipated events</b></p> <p>Has planning being undertaken and is there sufficient flexibility in the timing and resources available for the programme to be able to manage and respond to unexpected environmental or political hazards?</p>	<ul style="list-style-type: none"> <li>Discuss with the funding body, organizational management and other stakeholders the likelihood of, and how a response will be developed for unanticipated events. For example, backup locations for interviews, implications of and managing delays and, how to destroy hard copies of identifiable data, etc.</li> <li>Have clear security and safety protocols, including appropriate data protocols (what to do with any sensitive data being physically stored).</li> </ul>
<p><b>Ensuring ongoing ethical review</b></p> <p>Is a process and system in place to ensure ongoing monitoring and management of ethical issues as they arise?</p>	<ul style="list-style-type: none"> <li>Assign ethics focal point.</li> <li>Update any Ethics Review Board of any significant ethical issues arising that may change the nature of the evidence generation.</li> <li>Ensure that there are regular reviews of ethical issues arising and that staff can raise this issue with supervisors in regular meetings.</li> </ul>

ISSUE AND QUESTION	POSSIBLE RESPONSES
<b>Child protection protocols</b> Are the implementing parties aware of their obligations under the various child protection policies or ethical procedures? Are there clear protection and data protocols that have been developed reflecting these policies and procedures?	<ul style="list-style-type: none"> <li>• Ensure all staff are aware of implementing parties' child protection policies or ethical procedures before commencement of the project.</li> <li>• Discuss child protection policies or ethical procedures in ethics training, including detailed instructions on referral pathways when there is a need for case management, and mandatory reporting processes.</li> <li>• If useful, relevant and safe, create and provide general information (e.g. on services available, privacy measures that participants and their family/communities can take when using mobile phones or the internet, etc.) that data collectors can hand out to participants after a survey, interview or focus group.</li> </ul>
Understanding power relations	
<b>Inclusion/exclusion</b> Have steps been taken to ensure that marginalized groups are not excluded from samples? e.g., children with disabilities, minority groups, particular ages, castes, etc...	<b>Options:</b> <ul style="list-style-type: none"> <li>• Ensure the representation of marginalized groups in samples.</li> <li>• Note and justify any exclusions in reports and clearly identify the implications of not including them.</li> </ul>
<b>Relationships between investigators and communities</b> Have local communities and caregivers been consulted and fully informed about the focus, process and proposed methods?	<ul style="list-style-type: none"> <li>• Determine key stakeholders and understand local power relations so that particular communities are not unduly excluded in consultations.</li> <li>• Ensure support from key stakeholders and representatives – do not proceed otherwise.</li> <li>• Understand that those in power may tend to direct investigators away from minority groups if they are concerned about their political and personal positions. Try to engage these communities but be sensitive to potential threats to them if they are involved.</li> </ul>
<b>Social dynamics</b> Have social dynamics, including gender issues, been accounted for in the selection of participants and the design and methodology used to collect information?	<ul style="list-style-type: none"> <li>• Train staff on social hierarchies, gender roles and power imbalances and their consequences. Allow time for discussion regarding how these manifest both within the communities involved in the project, within the data collection team itself, and in the interactions between different actors. Given that some if not all data collection staff will originate from these communities, this is important and a vital step in understanding the context.</li> <li>• Ensure that you consider the social and gender dynamics at both the inception phase, to inform staff recruitment, as well as during the planning phase (determining the survey methodology, selecting the location, writing interview questions, assigning data collectors, and determining potential privacy issues and confidentiality and security protocols).</li> <li>• Social and gender dynamics should also be considered when communicating the findings in terms of the platforms for dissemination, recipients of reports and any events involved in the communication programme.</li> </ul>
<b>Relationships between different children</b> Is there appropriate representation amongst the children who are participating? Have concerted efforts been made to ensure that all children are comfortable and able to have a voice within focus groups and other communal evidence-generation activities?	<ul style="list-style-type: none"> <li>• Ensure that facilitators are adept at identifying and managing power dynamics between children and ensuring that all children are heard.</li> <li>• To support facilitators consider (1) incorporating role-playing exercises into staff training, with time to discuss afterwards what worked well and what could be improved; (2) including a piloting phase in which more skilled facilitators are paired with weaker ones to allow time for mentorship; (3) including a quality control mechanism by which both the data collection process and the data itself is quickly assessed to flag any potential problems. Depending on the method(s) employed this could include reviewing FGD notes at the end of each day, weekly supervision meetings, running calculations of inter-rater reliability, etc.</li> </ul>



ISSUE AND QUESTION	POSSIBLE RESPONSES
<p><b>Relationships between adults and children</b></p> <p>Are procedures in place that describe what to do if an adult/authority figure wishes a child to participate in evidence generation but the child clearly does not wish to do so?</p>	<ul style="list-style-type: none"> <li>• Determine beforehand whether parents tend to push their children to participate and the factors encouraging this in the participating community. If this is likely to be driven by factors such as bribery or coercion by authorities, identify ways to address these issues.</li> <li>• If parents pressurize children who do not wish to participate, explain again to the parent that participation is voluntary and that the child does not need to participate. If they insist, design a short, general activity for the child to do (such as a quick survey or drawing exercise relevant to the topic at hand, but avoid sensitive issues and keep the activity short). For a focus group, allow the child to sit there quietly without participating and make sure that the children understand that this is acceptable.</li> </ul>
<p><b>Relationships between investigators and children</b></p> <p>Has everything possible been done to make children feel comfortable, safe and respected? This includes the location, study design, methods used to collect information, and other relevant factors.</p>	<ul style="list-style-type: none"> <li>• Rethink your locations, the design and the methodology used to ensure that the process is child- and age-appropriate and relevant to the competencies and the interests of children.</li> <li>• Ensure that any investigator or data collector has the sensitivity, patience and (preferably) experience in undertaking evidence generation involving children. (Remember: the best time to do this is when recruiting staff, so consider these points when writing job descriptions or terms of reference, and designing job interview questions.)</li> <li>• Design questions that are relatively open and not overly directive.</li> <li>• Consult with children before producing findings to ensure that the children's key messages have been understood appropriately.</li> <li>• Consider providing feedback to children on the findings, and/or producing child-friendly reports.</li> </ul>
<b>Harms and benefits</b>	
<p><b>Consideration of benefits</b></p> <p>Are there any direct benefits to the children involved in the evidence generation?</p>	<p><b>Options:</b></p> <ul style="list-style-type: none"> <li>• Explain to children and families clearly what the benefits may be to children in future humanitarian contexts (benefits should, at a minimum, impact future children in humanitarian contexts if not those directly involved).</li> <li>• Determine if the evidence generation programme includes activities that can engage children in recreational activities or activities that empower or build their skills.</li> <li>• Ensure that children are consulted in determining the findings of the report and that they can see the results of their contributions (e.g. child-friendly reports).</li> <li>• Determine if findings can directly contribute to increasing access to services and infrastructure available to children in the shorter term.</li> </ul>
<p><b>Serious risks to children</b></p> <p>Are there serious risks to children if they participate in the evidence generation?</p>	<p><b>Options:</b></p> <ul style="list-style-type: none"> <li>• Do not proceed.</li> <li>• Determine if secondary data can be used (administrative data, such as health service records or other relevant data that is routinely collected and available) or consult service providers or other adult stakeholders to locate the information required – noting the limitations of this approach in any report.</li> </ul>
<p><b>Protection protocols</b></p> <p>Are clear protection protocols established, including staff codes of conduct, mandatory reporting of abuse processes, and services for when children identify an immediate need for support?</p>	<ul style="list-style-type: none"> <li>• Create, utilize and train staff on relevant Codes of Conduct for Staff.</li> <li>• Discuss with service providers how to best meet children's needs identified during the evidence generation.</li> <li>• Create a protection protocol which includes: <ul style="list-style-type: none"> <li>• approaches to mandatory reporting of abuse;</li> <li>• referral pathways to meet children's immediate needs for services;</li> <li>• approaches for data collectors to adopt if a child becomes distressed during data collection.</li> </ul> </li> </ul>

ISSUE AND QUESTION	POSSIBLE RESPONSES
<b>Environments</b> Is the physical location for evidence generation and the route to this location safe for children?	<ul style="list-style-type: none"> <li>Consult with local stakeholders on: <ul style="list-style-type: none"> <li>the best location to ensure the privacy and security of children as appropriate to that community (e.g. an interviewer being alone with a child may be inappropriate).</li> <li>the safest route and transport for children if the location is not in their immediate environment or if their immediate environment contains serious threats that restrict movement.</li> </ul> </li> <li>Do not proceed if there is no safe location for the data collection.</li> </ul>
<b>Security of staff</b> Are procedures in place to ensure that staff are safe in the field?	<ul style="list-style-type: none"> <li>Obtain input from longstanding or respected actors doing similar work (INGO, NGO, etc.) to determine the most appropriate safety arrangements for data collectors and investigators in the field, e.g., groups of at least 3, whether a 'male escort' is needed, etc.</li> <li>Make sure that you have budgeted for logistical and other measures to ensure the safety of staff.</li> <li>Determine safe routes for staff.</li> <li>Make sure that both the field staff (including investigators, drivers, interpreters, etc.), as well as managerial and operations staff, understand the geography and the political and social issues within the programme area(s) and that a clear system exists for information and communication between these groups.</li> <li>Ensure that supports are available for staff to debrief and to access psychosocial care should they need it at any point during the evidence generation.</li> <li>Have clear processes to determine when staff need to be taken out of the field for psychological reasons.</li> <li>Have clear procedures on what staff need to do in the case of unexpected hazards. Train staff on these protocols.</li> </ul> <p><b>Resources: A Code of Practice for the Safety of Social Researchers</b>  <a href="http://the-sra.org.uk/wp-content/uploads/safety_code_of_practice.pdf">http://the-sra.org.uk/wp-content/uploads/safety_code_of_practice.pdf</a></p>
<b>Methods</b> Have you considered the methods and approaches to engaging children and the impact these may have on them?	<ul style="list-style-type: none"> <li>Consider and discuss with local stakeholders issues such as the timing, duration, presence of adults and the nature of the data collection. (Questions to consider include: Is the questionnaire too personal or too impersonal? Could it be easier because it is quicker? Is it possible to adopt open-ended questions that encourage discussions and allow self-expression?)</li> <li>Check that data collectors understand children's meanings, and do not just assume that they do.</li> <li>Consult with actors who have undertaken data collection among similar groups and/or on similar topics to identify what went well (both intended and unintended positive consequences) and what did not go well (unintended negative consequences). Apply this learning to your work!</li> </ul>
<b>Taking photographs or videos</b> Have prior consultations been held with those best able to assess the political, social and cultural ramifications of taking or disseminating photographs and videos?	<ul style="list-style-type: none"> <li>Undertake consultations to determine the risks of taking or disseminating photographs or videos.</li> <li>Seek assent or consent (as relevant) from caregivers and/or children whose photographs or videos are taken. (If no caregivers see informed consent section).</li> <li>Reflect on the depiction of children in photographs and videos, avoiding wherever possible, stereotypes and over-simplistic messages.</li> </ul>



ISSUE AND QUESTION	POSSIBLE RESPONSES
<b>Informed consent</b>	
Is ongoing consent or assent planned if the programme is longer term, has to change, or if new risks arise?	<ul style="list-style-type: none"> <li>• Determine if informed consent or assent is needed (it usually is!) and the best way to obtain it given the capacities of the participants and their caregivers.</li> <li>• If the programme is longer than six months, plan to obtain informed consent from caregivers and children at regular intervals.</li> <li>• If the programme changes, including changes to venues or agreed methods or disruption of regular group activities (e.g. significant changes to the composition of focus groups or workshop participants where a strong and positive and trusting group dynamic has been established) ensure that informed consent from children and caregivers is obtained again before continuing.</li> </ul>
Are procedures in place if children wish to participate but parents or stakeholders do not want them to?	<ul style="list-style-type: none"> <li>• Determine the fears or concerns that parents have and see if they can be addressed.</li> <li>• Do not proceed if the concerns cannot be addressed, particularly if participation will cause tensions between adults and children or will put the children at risk.</li> <li>• Determine if there are alternate evidence generation activities that would be acceptable to parents and stakeholders.</li> </ul>
Are procedures in place if potential child participants don't have caregivers?	<ul style="list-style-type: none"> <li>• Determine if the children have the competencies and maturity to understand the nature of the evidence generation, their roles, and potential risks and implications. If children are able to understand all of these, seek informed consent only from these children and allow them to participate (consider, if possible, cognitive testing).</li> <li>• Determine if there is a guardian who is familiar with the child/children and can provide informed consent on behalf of the child/children.</li> </ul>
<b>Privacy and confidentiality</b>	
<b>Privacy</b> How will privacy be maintained both when recruiting children to participate and during the evidence generation itself?	<ul style="list-style-type: none"> <li>• If the activity relates to a sensitive subject, carefully frame the purpose of the activity for the broader community. For example, if the aims and objectives of the activity relate to well-being, even in the midst of violence, make sure it is clear that evidence is being collected about well-being, not details of the violence. Participants should be told exactly what types of questions will be asked and about what types of topics.</li> <li>• Make sure the location for the evidence generation allows for privacy and plan what to do if privacy is not possible. E.g. change surveys so they ask generic questions rather than personal ones (e.g., Is violence towards children common in your community? versus Have you experienced violence?); engage parents or caregivers, etc.</li> </ul>
<b>Confidentiality: data</b> Do clear protocols exist on how to de-identify data as soon as possible, to protect identified data, to store and transmit data safely, and to destroy the data when necessary?	<p>Ensure clear data protocols are in place that describe:</p> <ul style="list-style-type: none"> <li>• When and how data will be de-identified;</li> <li>• Who will have access to identified data (limit number of persons to absolute minimum);</li> <li>• The means to ensure the data is secured when stored (locks, encryption, passwords) or when it is being transmitted (e.g. consider encryption, or when physically transporting the data on hard drives, use passwords etc.);</li> <li>• When and how data will be destroyed;</li> <li>• When data is in hardcopy and evacuation is required, or the facilities become unsafe, who will destroy the data and how they will destroy the data?</li> </ul>

ISSUE AND QUESTION	POSSIBLE RESPONSES
<p><b>Children's biological materials</b></p> <p>Do clear protocols exist outlining that biological materials will not be used elsewhere, how and where the materials will be stored, and when and how to destroy the materials safely?</p>	<p>Ensure clear data protocols are in place that describe:</p> <ul style="list-style-type: none"> <li>• When and how biological materials will be de-identified (if possible);</li> <li>• Who will have access to the biological materials;</li> <li>• Clear agreement that materials will not be used elsewhere, or if they are to be transported elsewhere (especially overseas) that strict confidentiality protocols will be observed including compliance with relevant laws and regulations;</li> <li>• How the materials will be securely stored and who will have access to the materials (and with what limits);</li> <li>• How to safely destroy the materials.</li> </ul>
<p><b>ICT:</b></p> <p>Are the privacy settings of the technologies being used understood by everyone using them?</p>	<p><b>Options:</b></p> <ul style="list-style-type: none"> <li>• If possible encrypt data;</li> <li>• Use the highest possible privacy settings;</li> <li>• Unless absolutely necessary use platforms that are password protected or have limited access;</li> <li>• If using web-based platforms where children can comment or post other media, have someone checking these to ensure that children are not identified or that comments are not inappropriate;</li> <li>• Try to avoid keeping data on cloud drives for any extended period of time, and, where necessary, ensure they are backed up.</li> </ul>
<b>Payment, compensation, and ancillary services</b>	
<p><b>Paying children for participation</b></p> <p>Have the most recent local legislation and international humanitarian laws regarding child labour and payment been reviewed by someone on the project team? Have local organizations been consulted as to how or whether it is appropriate to provide payment or other compensation to children for participation?</p>	<ul style="list-style-type: none"> <li>• Understand local laws and customs regarding payment of children;</li> <li>• Understand relevant international humanitarian law and human rights conventions;</li> <li>• Prior consultation with humanitarian actors and/or others doing similar work in the same area is required to determine the local laws on child labour and the nature of any compensation or payment to children participating in evidence generation;</li> <li>• Consider evidence generation programmes that provide non-material benefits for children through participatory or therapeutic approaches and engagement, or communal benefits such as educational tools or materials that can be used by all children exclusively within shared spaces;</li> <li>• If children are doing work that adults would be paid for, collecting data, etc. and, particularly if they may miss out on other opportunities for employment, payment should be considered at rates that are commensurate with local wages and/or stipends from other humanitarian actors, but that will not create significant tensions or resentment;</li> <li>• Consider compensating children and families for out-of-pocket expenses relating to participating (e.g. travel expenses). However, again, prior consultation should be undertaken to determine any negative implications.</li> </ul>
<p><b>Disassociating the evidence-generation programme from aid</b></p> <p>Has every effort been made to ensure that potential participants do not associate evidence-generation activities with humanitarian services or aid programmes?</p>	<ul style="list-style-type: none"> <li>• In pre-evidence-generation consultations, as well as during the consent process, explicitly state and stress to communities that collecting information is separate from receiving services or material support from humanitarian aid agencies (unless the data collection is strictly tied to provision of direct aid). Inform them of the reason the information is being collected and that, even if it is an evaluation of a programme, participation by children will not affect access to services or aid.</li> </ul>

ISSUE AND QUESTION	POSSIBLE RESPONSES
<b>Communication of results</b>	
<b>Transparency</b> Has a clear and transparent process been developed for the dissemination of results, ensuring that all stakeholders, including children are aware of the products, audience and platforms for dissemination?	<ul style="list-style-type: none"> <li>• Consult communities prior to undertaking evidence generation on the best way to communicate the findings to the community, who the audience should include and how the results' implications will be addressed.</li> <li>• During the consent process explain to communities, participants and parents/caregivers, how and in what form the results will be disseminated and to whom.</li> </ul>
<b>Final Community Consultation</b> Is a final consultation planned with children and key community advisors to ensure that results are a true reflection of the childrens' opinions, attitudes and experiences and that no stigma or negative repercussions to participants and their communities will result from their dissemination?	<ul style="list-style-type: none"> <li>• Consult communities on the best methods or forum to test and validate the findings with children and the community, who the audience should include and how the implications of results will be addressed.</li> </ul>
<b>Ensuring the results are accessible:</b> Are results accessible to child participants and the participating communities?	<ul style="list-style-type: none"> <li>• Consider producing child-friendly reports.</li> <li>• Ensure reports are translated into the relevant languages of child participants and the participating communities.</li> <li>• Determine the best ways for reports to be shared with these communities (e.g. at a meeting, in electronic versions, using animations, pictorially, etc.).</li> </ul>

## APPENDIX 2

### ETHICAL PRINCIPLES AND REQUIREMENTS IN RESEARCH INVOLVING CHILDREN IN HUMANITARIAN CONTEXTS: SUMMARIES OF AVAILABLE LITERATURE AND GUIDANCE

**Feinstein, C., and O’Kane, C. (2008).** *Ethical Guidelines for Ethical, Meaningful and Inclusive Children’s Participation Practice*, Save the Children Norway

<file:///E:/Ethics%20and%20Emergencies/Feinstein-OKane-2008%20Ethical%20Standards%20for%20Child%20Participation.pdf>

The following reproduces the ethical principles and considerations identified by Feinstein and O’Kane which provided the ethical framework for the Global Report: Adults’ War and Young Generations’ Peace, Save the Children Norway.

#### **Principles**

- Avoiding harm to participants
- Child protection (including in abuse cases and in other cases, e.g. disability, out-of-school, children without carers)
- Informed consent
- Confidentiality
- An ethical approach. This approach recognizes the power imbalance between children and adults – and/or between different groups of children and young people – and develops strategies to address it.
- Dealing with Adult Child Power Relations. The difference between children’s and adults’ views may create conflict. There is a need to ensure that children’s views are not ignored by adults and that children do not face increased risk as a result of any perceived differences in opinion. Efforts to involve parents, step-parents, teachers, head teachers, community members, NGO staff and managers, government officials and other key adults in children’s lives throughout the evaluation process can help them to develop behaviour and attitudes which support children’s expression.
- An inclusive approach. This means that equal opportunities to take part are created for all girls and boys, no matter what their age, ability, etc..
- Recognising and reporting on the diversity of children’s experiences (using disaggregated data, understanding adults’ views of children, ensuring appropriate representation and understanding and appreciating that children are not a homogenous group).
- Timing of the evidence generation. It is critical to ensure that research, data collection and evaluation planning occur at times when children are available and can meaningfully and effectively engage in these processes and activities. In particular, workshops and more intensive activities should be planned at times that do not interfere with children’s school work, especially during exam periods.

- **Motivation.** Transparency is needed regarding the criteria and motivation for participation. It is important to manage any expectations about material or symbolic ‘rewards’ for participation. It is also important to ensure that the work does not lead to an increase in status or attention for individuals or groups leading to tensions between groups and/or within communities.
- **Wider accountability.** This includes providing feedback on results and findings to children, communities and other stakeholders who participate, acknowledging the capacities of children and responding to and acting upon their concerns, recommendations and priorities. The development and distribution of age-friendly summary reports (in local languages) from key workshops or processes is one way to support such feedback.

## Checklist

### Some Key Considerations for Ethical Research and Discussions with Children and Young People

- Ensure effective communication and coordination systems are in place with all stakeholders (from local to national/global level).
- Ensure that all researchers are introduced to and fully understand the organization’s Child Protection Policy and that they have signed it or a similar Code of Conduct as part of the contracting procedure.
- Assess the risks to participants before you begin the research and make sure you have strategies to deal with or minimize any risks.
- Plan research and evaluation activities at times that suit children and young people, and at times that do not interfere with their school work (or important household or other responsibilities).
- Ensure that children and young people have access to all materials and support needed to carry out the research and evaluation activities safely and effectively.
- Make sure that all participants have given their informed consent to their involvement and that they can withdraw this consent at any point. Make sure that parents/step-parents/carers/guardians understand, accept and support the process that their children are involved in, and that they give their consent.
- In addition, seek the support of the wider community/school and people who are also important to the lives of the children and young people locally, especially to raise awareness about children’s rights for all children.
- Make sure that you respect the privacy and anonymity of the children and young people during research and evaluation processes – while being prepared to deal with any disclosures.
- Ensure that children’s views and experiences remain anonymous and confidential in written documents or media reports – particularly if negative experiences are being shared. For example, if sharing a quote or story, provide key background information to indicate from the source, but not sufficiently to identify the child/children.

- Be prepared to take responsibility when children need immediate support or protection, especially in relation to distress or possible disclosure.
- Make arrangements for follow up psycho-social or other forms of support to individual children if they need it. Make sure that methods are used which allow all children to actively participate according to their age, abilities, etc.
- Make sure that issues of discrimination are dealt with and that the research is conducted in a non-discriminatory and inclusive way which particularly allows the voices of groups subject to discrimination to be heard.
- Check with children and young people about their spoken or written words or drawings and any interpretations of them. Be clear with children and young people if and how these will be used – while respecting confidentiality as above.
- Make sure that issues of material or symbolic rewards for participation are addressed in a transparent and fair way and that all expectations are managed in this respect.
- Make sure good quality feedback is provided to all those involved, including the wider community.

**Hart, J., and Tyrer, B. (2006).** *Research with Children Living in Situations of Armed Conflict: Concepts, ethics and methods, Refugee Studies Centre Working Paper No 30, Oxford*

The authors suggest the following list of key questions and strategies that may be considered prior to and throughout research involving children and young people in situations caused by conflict (pp.18-19).

1. What concerns are likely to exist amongst the immediate community about bringing children together for research activities? How can these be dealt with?
2. How might such concerns relate to the specific composition of groups of children – for example, mixed groups of males and females or children from different class, caste or ethnic groupings? How can these be dealt with?
3. Are the local political-military actors likely to take an interest in these activities? If so, what relationships may be needed to be built and what assurances received and given?
4. Does the schedule of issues to explore through research contain anything that participating children, their families, communities and political-military actors might consider inappropriate?
5. In the event that the research creates upset for individual children or division amongst participants or adverse reaction from others, what resources – individual or organizational – exist to provide back-up support (including psycho-social support) in addressing such problems?
6. What spaces, if any, exist within the immediate area where it is possible to conduct research with children and young people in a manner that ensures security and privacy without raising suspicion?

7. Which areas need to be avoided during research activities to avoid risk of danger to children such as landmines, child abduction or armed conflict?
8. How can the research action plans for different areas be flexible enough to take into consideration the socio-political context, the possibility of strikes, continued conflict, insecurity or instability, disruption caused by elections, etc.?
9. How can children and young people be supported to safely engage and participate in political/policy making processes that concern them (such as the formal peace talks, constitutional election process, and presidential elections) while also being protected?

Strategies to identify and minimize risks to children and young people in situations of conflict and post conflict include:

- The need to understand the local context and gather information to identify and analyze potential risks. It is especially important to understand the context of the conflict and its impact on various aspects of the community, family and children's lives. It is also important to understand the policy environment and existing decision making structures within the local community, at district or national level, as appropriate.
- Assessing the risks of children meeting with different target groups, to ensure that children will not face significant risks by interacting with certain stakeholders, and support preparations for safe, meaningful and influential interactions between children and key adults. Share background information with children about the adults that they are considering interacting with, such as, government officials, members of parliament, rebel leaders, religious or cultural leaders. Share information about the roles and responsibilities of key stakeholders, the kind of work they do and the influence they have.
- Working together with children to help them analyze and plan the most safe and effective ways to influence these key adults in positive ways. Remember to refer to and apply good practice in supporting children's participation which promotes the safety and protection of children. If risks are deemed too high then consider other appropriate and safer alternatives – for example, adults speaking or advocating on behalf of children while keeping children's voices at the centre of the debate.
- The importance of having a flexible research process which keeps the principle of 'do no harm' at the forefront of all planning so that if strikes or political instability occur, the work with children and adults in communities can be postponed until it is safe enough to continue.
- The need to hold meetings with different stakeholders – community leaders, leaders of political parties, religious leaders – and discuss with them the importance of listening to children's views and to ensure that children and the spaces closest to them (schools, etc.) are protected from involvement and incursions by armed forces and groups or political party interests, manipulation and propaganda. Adults need to think about what they can do to support children – in terms of ensuring neutrality, transparency and trust.
- The need to prepare children for any consequences of actions – through a comprehensive child protection plan/strategy.



- The importance of ensuring that psycho-social support is available (for immediate support and/or for referrals of children, young people or adults) throughout the research/evaluation process.
- The need to make national and international advocacy links and work to prevent abductions and the recruitment of children into conflict.
- The need to identify any high risk areas which should be avoided during the research activities.

**Sumathipala, A., Jafarey, A., De Castro, L., Ahmad, A., Marcer, D., Srinivasan, S., Kumar, N.K., Sutaryo, S., Bhan, A., Wadeyaratne, D., Beneragama, S., Jayasekera, C., Edirisingha, S., Siriwardhana, C. and Siribaddana, S. (2007). *The Draft Statement/Guidelines for Disaster Research, Working Group on Disaster Research and Ethics***

<https://globalhealthtrials.tghn.org/articles/draft-statementguidelines-disaster-research/>

The following are excerpts from the Draft Guidelines for disaster research that provide ethical guidance on the principles, nature and determination of when and how research may be justified within these contexts.

### **1. Relevance to disaster situations**

- a) Research planned to be conducted after a disaster should be essential and is not possible in non-disaster situations.
- b) The objectives of all potential research in disasters should be weighed very carefully for their potential contribution to the survivors, and for their value in future disaster situations.

### **2. Informed consent and voluntariness**

- a) Any research is only to be carried out with the prior, free and informed consent of the person concerned based on adequate information.(...)
- c) Survivors of disaster situations are particularly vulnerable and should not be subjected to inducement. (...)
- f) The requirement for research on children affected by disasters cannot be ruled out. However, due to their greater vulnerability, the investigator will have to justify the need to use children as research participants. The informed consent process will have to incorporate mechanisms of proxy consent by their parents or guardians and include provision from permission by the child whenever applicable. The reviewers will look very carefully at the process of consent involving children who have lost one or both parents in the disaster.

### **3. Community consultation and participation**

- a) Community participation before and during the research is essential in disaster-affected communities.
- b) The researchers and review process need to identify the communities that may be affected by the research and consult with them. The research team must describe a preliminary

community mapping/scoping exercise to ensure familiarity with the community as well as identify local resources who will support ethical execution of the research.

#### **4. Non-exploitation**

- a) The selection of research participants must be made based on scientific reasons and not based on accessibility, cost, gender or malleability.
- b) The research should not impose additional burdens on people who are already traumatised, and on the local infrastructure.

#### **5. Dignity, privacy and confidentiality**

- a) Given the circumstances that survivors of a disaster face, extra care must be taken to protect the privacy and confidentiality of individuals and communities.
- b) In the collection of data and human biological material, human dignity must be respected for both survivors and the deceased.
- c) Similarly, stringent standards must be maintained for the storage and possible sharing of human biological material and data.

#### **6. Risk minimization**

- a) Since disaster-affected populations are particularly vulnerable, it must be ensured that the conduct of research imposes the absolutely minimal risk.

#### **7. Institutional arrangements**

- a) Institutions that sponsor and conduct research should recognise that a stronger ethical obligation is required in disaster-related research.
- b) Research in disasters should be coordinated with other disaster relief activities.
- c) Research should not disrupt or further burden the existing infrastructure.

#### **8. Public interest and distributive justice**

- a) The research undertaken should provide direct or indirect benefits to the researched group, the disaster-affected community or future disaster affected populations.

#### **9. Dissemination of results**

- a) Transparency in the dissemination of results should be a prior condition for the conduct of research in disasters. (...)
- c) Efforts should be made to use the results of research to influence the formulation and modification of policy.
- d) The presentation of the results of research to the community who participated in the research, and to the public, should be after a process of peer review has validated the conclusion reached.
- e) The relevant results need to be presented in understandable language to research participants and the participating community.

**WHO (2007) WHO Ethical and Safety Recommendations for Researching, Documenting and Monitoring Sexual Violence in Emergencies**

[www.who.int/gender/documents/OMS\\_Ethics&Safety10Aug07.pdf](http://www.who.int/gender/documents/OMS_Ethics&Safety10Aug07.pdf)

This WHO publication identifies the following eight safety and ethical recommendations on monitoring sexual violence in emergencies (p.9):

1. The benefits to respondents or communities of documenting sexual violence must be greater than the risks to respondents and communities.
2. Information gathering and documentation must be done in a manner that presents the least risk to respondents, is methodologically sound, and builds on current experience and good practice.
3. Basic care and support for survivors/victims must be available locally before commencing any activity that may involve individuals disclosing information about their experiences of sexual violence.
4. The safety and security of all those involved in information gathering about sexual violence is of paramount concern and in emergency settings in particular should be continuously monitored.
5. The confidentiality of individuals who provide information about sexual violence must be protected at all times.
6. Anyone providing information about sexual violence must give informed consent before participating in the data gathering activity.
7. All members of the data collection team must be carefully selected and receive relevant and sufficient specialized training and ongoing support.
8. Additional safeguards must be put into place if children (i.e. those under 18 years) are to be the subject of information gathering.

**Ford, N., Mills, E.J., Zachariah, R. and Upshur, R. (2009). *Ethics of Conducting Research in Conflict Settings, Conflict and Health*, 3 (7), pp.1-9.**

Below are the benchmarks identified in the paper along with the definitions provided.

**Collaborative Partnership.** Researchers should engage in partnership with national and/or international research institutions as relevant and appropriate.

**Community engagement.** Researchers should respect the community's values, culture, traditions, and social practices; involve the community in the design and implementation of research through a consultative process; and share fairly any financial and other rewards of the research.

**Social value.** Beneficiaries should be clearly specified, and the importance of the health problems being investigated and the prospect of value of the research for the beneficiaries made clear... Efforts should be made to avoid diverting resources from health services for the conduct of research.

**Scientific Validity.** Research design should optimize the possibilities of achieving the social value requirements. Research should be feasible given the social, political, and cultural environment and with sustainable improvements in the local health care and physical infrastructure.

**Fair selection of participants.** The study population should be selected in such a way as to ensure scientific validity and minimize the risks of the research.

**Favourable Harm-Benefit Ratio.** Protocol should clearly assess potential harms and benefits to the study participants and the harm-benefit ratio for the community.

**Informed consent.** The study community should be involved in establishing appropriate recruitment procedures and incentives for the participants. Consent procedures should be acceptable and practical within the study community.

***The Inter-Agency Standing Committee (IASC) Task Force on Accountability to Affected Populations (AAP) (2011). The Five Commitments to Accountability to Affected Populations***

<https://interagencystandingcommittee.org/accountability-affected-people>,

The IASC Guidance promotes five commitments to accountability.

1. **Leadership/Governance:** Demonstrate their commitment to accountability to affected populations by ensuring feedback and accountability mechanisms are integrated into country strategies, programme proposals, monitoring and evaluations, recruitment, staff inductions, trainings and performance management, partnership agreements, and are highlighted in reporting.
2. **Transparency:** Provide accessible and timely information to affected populations on organizational procedures, structures and processes that affect them to ensure that they can make informed decisions and choices, and facilitate a dialogue between an organization and its affected populations over information provision.
3. **Feedback and Complaints:** Actively seek the views of affected populations to improve policy and practice in programming, ensuring that feedback and complaints mechanisms are streamlined, appropriate and robust enough to deal with (communicate, receive, process, respond to and learn from) complaints about breaches in policy and stakeholder dissatisfaction. Specific issues raised by affected individuals regarding violations and/or physical abuse that may have human rights and legal, psychological or other implications should have the same entry point as programme-type complaints, but procedures for handling these should be adapted accordingly.
4. **Participation:** Enable affected populations to play an active role in the decision-making processes that affect them through the establishment of clear guidelines and practices to engage them appropriately and ensure that the most marginalized and affected are represented and have influence.
5. **Design, Monitoring and Evaluation:** Design, monitor and evaluate the goals and objectives of programmes with the involvement of affected populations, feeding learning back into the organization on an ongoing basis and reporting on the results of the process.

## APPENDIX 3

### EXCEPTS FROM UNICEF PROCEDURE FOR ETHICAL STANDARDS IN RESEARCH, EVALUATION, DATA COLLECTION AND ANALYSIS

**Document Number: CF/PD/DRP/2015-001**

**Effective Date: 01 April 2015**

**Issued by: Director, Division of Data, Research and Policy (DRP)**

#### 1. Rationale

To underpin its programmes, policy and advocacy work, UNICEF invests substantially in conducting, as well as commissioning, research, evaluation and data collection and analysis in order to create a strong evidence base to support the realization of the rights of every child, especially the most disadvantaged.

In light of UNICEF's strategic agenda to harness innovation and deepen and widen the evidence base to drive and sustain global progress towards the realization of children's rights, ensuring ethical conduct in is imperative. This is necessary both in its own right and as a significant contributor to ensuring quality and accountability in the evidence generation process, especially when it involves children.

Ethical reflection and conduct in evidence generation is requisite in an equity based framework. A focus on the most marginalized, and frequently, the most vulnerable population groups necessitates measures to ensure that participants are respected and that they are protected throughout the process. Further, efforts must be taken not only to mitigate against risks to participants, but also to staff and to the organization as a whole.

In order to ensure the protection of, and respect for, human and child rights within all research, evaluation and data collection processes undertaken or commissioned by UNICEF, this procedure is designed to achieve the following objectives:

- To establish minimum and binding standards for ethical research, evaluation and data collection and analysis processes in UNICEF globally; and
- To ensure effective processes and accountability for ethical oversight of these processes.

This procedure is complemented by, and builds on, the pre-existing Strategic Guidance Note on Institutionalizing Ethical Practice for UNICEF Research and the Evaluation Technical Note No. 1, Children Participating in Research, Monitoring and Evaluation (M&E) — Ethics and Your Responsibilities as a Manager, UNICEF Evaluation Office, 2002.

#### 2. Applicability / Scope

- i. All UNICEF research, evaluation and data collection and analysis involving human subjects or the analysis of sensitive secondary data as outlined in Figure 1.

- ii. All research, evaluation or data collection processes (identified in para i. above) that are carried out, or commissioned by UNICEF sections – including Country Offices (COs), Regional Offices (ROs), and Headquarters sections (HQ) – both in partnership and independently. Where a UNICEF partner has its own mechanisms for ethical review, they may substitute for this procedure but only in the instances where partner ethical review processes meet the minimum standards laid out in this procedure.
- iii. This procedure will be reviewed within two years.

### 3. Definitions

**Assent** – Assent is the willingness to participate in research, evaluations or data collection by persons who are by legal definition too young to give informed consent according to prevailing local law but who are old enough to understand the proposed research in general, its expected risks and possible benefits, and the activities expected of them as subjects. Assent is similar to the process of informed consent. Assent by itself however, is not sufficient, however. If assent is given, informed consent must still be obtained from the subject's parents or guardian or a responsible adult.

**Confidentiality** – Confidentiality is the process of protecting an individual's privacy. It pertains to the treatment of information that an individual has disclosed in a relationship of trust, with the expectation that this information will not be divulged to others without permission.

**Evaluation** – Evaluation is a systematic and objective effort to determine the relevance, appropriateness, effectiveness, efficiency, impact and sustainability of development efforts, based on agreed criteria and benchmarks among key partners and stakeholders. It involves a rigorous, systematic and objective process in the design, analysis and interpretation of information to answer specific questions. It provides assessments of what works and why, highlights intended and unintended results, and provides strategic lessons to guide decision-makers and inform stakeholders.

**Ethical evidence generation** – Ethical evidence generation follows widely-held guidelines about what is ethical, moral and responsible (e.g. not plagiarizing others' work, not submitting questionable data, avoiding doing harm, ensuring just distribution of the benefits and risks of the research etc). Ethical evidence generation is reflective and explicitly considers its impact on both participants and the broader community throughout the research cycle from planning through to dissemination and monitoring and evaluation.

**Evidence generation activities** – For the purpose of this procedure, research, evaluations, data collection and analysis are collectively referred to as evidence generation activities.

**Final report** – For the purposes of this procedure a final report is a publically available report or a report targeted to a specific stakeholder (e.g. government) that is produced consequent to the interim or final findings of research, evaluation and data collection and analysis processes.

**Informed consent** – The voluntary agreement of an individual, or his or her authorized representative, who has the legal capacity to give consent, and who exercises free power of choice, without undue inducement or any other form of constraint or coercion to participate in research.

The individual must have sufficient knowledge and understanding of the nature of the proposed evidence-generating activity, the anticipated risks and potential benefits, and the requirements or demands of the activity to be able to make an informed decision.

***Institutional Review Boards (IRBs) or Ethical Review Boards (ERBs) or Committees*** – A specifically constituted review body established or designated by an institution to protect the rights and welfare of human subjects recruited to participate in biomedical or behavioral or social science research. IRBs attempt to ensure, both in advance and by periodic review, protection of subjects by reviewing research proposals and related materials. IRB protocols assess the ethics of research, evaluations or data collection and analysis and their methods, promote fully informed and voluntary participation by prospective subjects capable of making such choices (or, if that is not possible, informed permission given by a suitable proxy), and seeks to maximize the safety of subjects. In this procedure IRBs will be included in the term Ethical Review Boards.

***Privacy*** – The ability of an individual to control the extent, timing, and circumstances of sharing themselves (physically, behaviorally, or intellectually) with others. Privacy refers to the right of individuals to limit access by others to aspects of their person that can include their thoughts and identifying information.

***Primary data*** – The creation of new data via first-hand collection.

***Proposal*** – For the purposes of this procedure a proposal is a detailed overview of a planned research, evaluation or data collection and analysis project. Therefore, within this procedure, a protocol for research or data collection, or an inception report for an evaluation, would be considered a proposal.

***Research*** – The systematic process of the collection and analysis of data and information, in order to generate new knowledge, to answer a specific question or to test a hypothesis. Its methodology must be sufficiently documented to permit assessment and replication. Research at UNICEF should examine relevant issues and yield evidence for better programme and policy advice.

Secondary data – Information gathered from pre-existing sources or databases.

#### **4. The Principles Guiding this Procedure**

The minimum standards and procedures outlined in this document are guided by the following three principles as laid out in the Belmont Report on Ethical Principles and Guidelines for the Protection of Human Subjects of Research (1979). It should be noted that while these principles apply to all participants involved, children may be particularly vulnerable in the evidence generation process and appropriate considerations as elaborated in the Strategic Guidance Note on Institutionalizing Ethical Practice for UNICEF Research and the Evaluation Technical Note No. 1, Children Participating in Research, Monitoring and Evaluation (M&E) — Ethics and Your Responsibilities as a Manager can and should be reflected in the process. The following are the three principles that should inform ethical evidence generation:



i. **Respect**

All evidence-generating activities should ensure respect for all persons. Respect demands that individuals be treated as autonomous agents. An autonomous agent is an individual capable of deliberation about personal goals and of acting under the direction of such deliberation. To respect autonomy is to give weight to autonomous persons' values, preferences, and beliefs and to recognise their capability for self-legislation, their ability to make judgments, to state their opinions and to make choices.

In respecting an individual's autonomy, recognition is required that personal agency may be limited due to age, circumstance or personal capacities. In this context, respect for autonomy requires recognition of capabilities, power differentials and the degree of agency that an individual may have. In the context of children and other vulnerable groups respectful evidence generation needs to be situated in their lived experience with recognizing the reality of unequal relationships of power that frequently exist, creating environments that support these individual's personal agency and dignity.

ii. **Beneficence and Non-maleficence**

*Beneficence* – The principle of beneficence refers to the requirement that actions within evidence-generating activities promote the well-being of individuals, communities or society as a whole. The principle of beneficence requires the identification of clear benefits likely to arise from evidence and to reconsider proceeding if these cannot be articulated. Beneficence includes the concept of reciprocity, whereby the evidence generated is conveyed back to the participants so that they may triangulate findings, contextualize their participation and potentially gain from the knowledge disseminated.

*Non-maleficence* – The principle of non-maleficence, doing no harm, requires avoiding harm or injury to participants, both through acts of commission or omission. While the primary purpose of research, evaluation and data collection and analysis is to generate new evidence, this goal should never take precedence over the rights of individual participants. Non-maleficence requires an examination of the profile, competencies and skills of researchers and enumerators to ensure no harm comes to participants by virtue of inappropriate, unskilled or incompetent researchers or enumerators. It also requires explicit consideration of means to ensure the privacy of participants, their safety and any possible negative impacts arising from participation.

iii. **Justice**

The principle of justice requires that consideration is given to who benefits and who bears the burden of the evidence generation. This requires that due reflection is given to determining the appropriateness of proposed methods of selecting participants. Selection should not result in unjust distributions of the burdens and benefits of evidence generation. Such considerations are required to avoid the injustice that arises from social, racial, sexual, and cultural biases institutionalized in society.

## 5. Procedural Statements

The following are the minimum standards and required procedures for research, evaluation and data collection and analysis undertaken or commissioned by UNICEF (including activities undertaken by individual and institutional contractors, and partners) involving human subjects or the analysis of sensitive secondary data. These standards explicitly recognize and reflect the spirit and intention of the Declaration of Helsinki (1964) and its attendant amendments, emphasizing the importance of respect for and protection of human rights. More specifically, as relates to the involvement and focus on children in research, evaluation and data collection and analysis, these standards attempt to reflect the United Nations Convention on the Rights of the Child's (UNCRC) principles of the best interests of the child, non-discrimination and participation.

Within this procedure the principles and requirements for evidence generation are applied to four core ethical issues, namely; Harms and Benefits, Informed Consent, Privacy and Confidentiality, and Compensation and Payment. In addition, they also specifically articulate UNICEF's position on conflicts of interest and ethical funding of evidence-generating activities.

### 5.1 Procedures Specifically Relating to Harms and Benefits

- i. All proposals must justify why the evidence generation processes covered by this procedure are being undertaken. The justification must take into account pre-existing evidence or gaps in the evidence, and must explicitly reflect on the data sources and the particular methodology applied in order to ensure that the specific approach adopted has minimized any negative impacts on participants and their communities.
- ii. All proposals must justify why certain groups are included or excluded. The rights of vulnerable and marginalized groups to participate must be recognized and respected and, more particularly, measures should be taken to support the involvement or representation of under-researched groups. Respecting groups' and individuals' participation rights however needs to be weighed against any potential harms that may come to these groups consequent to their involvement or representation in evidence-generating activities.
- iii. In justifying the evidence generation process involving human subjects or involving sensitive secondary data, efforts must be made to ensure that the evidence or the data to support the evidence is not already available and publically accessible.
- iv. Throughout the evidence generation process, and articulated in both the proposal and the final report, should be consideration of any potential harms and benefits for participants, their families or wider community groups. An assessment of potential harms and benefits can and should be supported by a situational analysis (using available data) including local consultation. In the instance of local consultation (particularly with implementing partners), power relationships and their dynamics should be explicitly factored into the selection of stakeholders consulted.
- v. At the proposal stage, where the potential risks outweigh the potential benefits, consideration must be given to the modification or withdrawal of the proposal.

- vi. Throughout the evidence generation process and articulated in both the proposal and the final report are the methods or practices adopted to ensure that participants are not harmed as a consequence of their participation from the outset of the project through to its completion and dissemination.
- vii. All programmes must design and utilize appropriate methods, practices and data collection environments that minimize stress for participants. These processes must be explicitly noted in both the proposal and the final report.
- viii. Protection protocols for children and, where relevant, other vulnerable groups, must be in place to provide safe environments for data collection, to safeguard them from abusive or incompetent researchers/evaluators/enumerators, to respond to any safety concerns or grievances, and to refer them to local supports both during and after the evidence generation activity if necessary, given due consideration to the particular vulnerability of children and young people. For further information regarding measures to protect vulnerable participants in evidence generation processes see Annex (B) Privacy and Confidentiality.
- ix. When there is conclusive proof of definitive negative outcomes for participants or their communities during the course of the evidence generation, protection protocols should be enacted and an assessment undertaken by the project managers whether the project can be modified to prevent further negative outcomes or whether the project must be stopped.
- x. In all reports produced consequent to findings of research, evaluation or data collection and analysis, the privacy and confidentiality of participants should be assured with data de-identified at the individual level, or findings summarized to an appropriate level of aggregation, particularly in the instance of clear negative impacts such as stigma and reprisals.

The implications of the findings and any potential negative repercussions for particular groups should be considered and measures taken to frame the findings in such a way as to avoid these consequences. Where findings will significantly impact (negatively) on the health and well-being of groups or individuals, public disclosure and, where relevant, disclosure to specific stakeholders should be reconsidered.

These issues and relevant measures should be anticipated and noted in the proposal and (in the case of unanticipated challenges that arise post the proposal stage) addressed as they arise.

## *5.2 Procedures Relating to Informed Consent*

- i. When engaging human subjects, informed consent must be sought from all participants. The nature of the informed consent must be noted in the ethics section of the proposal and any final report.
- ii. Any project seeking to involve children as either participants, researchers or data collectors must, at minimum, comply with local legislation regarding the age or circumstances which allow for informed consent. In the absence of this legislation, evidence generation involving children and young people under the relevant age of majority as defined by local law must take into account their competencies and the circumstances relating to their autonomy, and,

where autonomy is limited or where cultural norms dictate, consent sought from a guardian, parent, or, when these are unavailable or inappropriate, a relevant caregiver or person responsible for the child's well-being.

- iii. In the instance where consent is required from a parent, guardian, caregiver or person responsible for the child's or the individual's well-being, where possible, and reflecting their capacities, assent must still be sought from the child or the individual themselves. In all evidence-generating activities children and, where relevant, adults, must be fully informed, utilizing tools that are reflective of their capacities as to the purpose of the activity and what their involvement will be.
- iv. Potential participants must be made aware of the voluntary nature of their participation. The decision whether to participate, including dissent or unwillingness to participate, must be respected. Participants must be appropriately informed that consent is negotiable and that they can withdraw at any point without any negative consequences.
- v. Local consultation should be undertaken to ascertain if informed consent needs to be obtained from community leaders, representatives or heads of households with due consideration of the prevailing power structures and hierarchies within communities and households. This consideration is required to ensure that marginalized groups and individuals are not prevented from participation due to the personal, political and social agendas of gatekeepers.

### *5.3 Procedures Relating to Privacy and Confidentiality*

- i. Measures must be taken, particularly in sensitive contexts where participants are likely to be highly vulnerable, to ensure participants' privacy during and after the data collection process.
- ii. In the data collection and collation process such measures to be taken may include de-identification of data and, in the instance where GPS collections are taking place, scrambling of coordinates, de-linking of data or assignation of broader geographical references.
- iii. Confidential participant information or data that is collected must be securely stored, protected and disposed of. This would include limiting access to raw identifying data through password protection of electronic data, physical locks and restricting staff who can access the identified data. For further information regarding measures to protect data see Annex (C) Anonymising and Storing Data.
- iv. Participants should be given a clear indication of who will have access to their private data and in what form.
- v. Any assurance to participants about confidentiality must also include explicit mention of the limits to this, with relevant staff prepared to act sensitively on safety concerns in accordance with the project protection protocols and local legislation pertaining to the reporting and disclosure of abuse.
- vi. Issues and measures taken to ensure privacy and confidentiality of participants must be noted in the ethics section of the proposal and the final report.

#### *5.4 Procedures Relating to Payment and Compensation*

- i. Payment must not be used to coerce, pressure or bribe adults or children to participate or to influence the nature of their responses.
- ii. Evidence generation processes must take social and cultural contexts into account and consult locally about payment and other forms of reciprocity to determine the nature or need for reimbursement, compensation or recognition.
- iii. In providing payment and compensation, explicit consideration must be given to the possibility and implications arising from the fact that payment may directly or indirectly raise unrealistic expectations or cause disappointment. In these instances, mitigation strategies must be explored and developed.
- iv. Explicit consideration needs to be given to the form, timing and amount of payment or compensation to ensure that financial costs are appropriately reimbursed and that the amount does not distort the decision to participate or the responses given.
- v. Issues and decisions related to payment and compensation must be noted in the ethics section of the proposal and the final report.

#### *5.5 Procedures Relating to Conflict of Interest and Funding*

- i. Any proposal presented to the senior management of a unit, office or division as well as proposals presented to review boards must include information regarding funding, sponsors and institutional affiliations.
- ii. Any actual or potential conflicts of interests relating to specific member/s of an ethical review board or panel existing or arising consequent to specific research, evaluations or data collection and analysis projects must result in the exclusion of the board member from all deliberations and consultations pertaining to the project/s in question.
- iii. Any actual or potential conflicts of interests relating to staff, contractors, contracting institutions or funders existing or arising consequent to research, evaluations or data collection and analysis must be disclosed in any proposal in accordance with UNICEF (2012) Financial Disclosure and Declaration of Interest Statements, Executive Directive CF/EXD/2012-003 to determine whether it is appropriate for the project to proceed see ANNEX (D) for further detail.
- iv. Where an evidence generation project is given appropriate authority to proceed, conflicts of interest should still be noted in all relevant proposals to ethical review boards or panels and research publications in accordance with the Procedure Relating to Quality Assurance for UNICEF Research.
- v. Funding for evidence generation must not be sourced from industry sectors or organizations identified within UNICEF's policy of zero tolerance as laid out in Building Alliances for Children – UNICEF Guidelines and Manual for Working with the Business Community (2001) and revised in Briefing Note on Screening Criteria for the Development of Corporate Partnerships. Further, all prospective funding bodies and institutions must follow the appropriate screening process undertaken by the Corporate Intelligence Fundraising unit of the Private Fundraising and Partnership section of UNICEF.